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**Mexican-American Men's Fathering of Children with a Chronic Health Condition**

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# Mexican-American Men's Fathering of Children with a Chronic Health Condition

**by**

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## Dedication

*To all the fathers who participated in this study, who believe in their children*

*To my friend Charles Sheffield, in his loving memory.*

*To a mentor and colleague, Kathy Shelby, RN, MSN, WHNP, in her loving memory*

*To Mrs. Victoria (Dean) Wood, my third grade teache*

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**Mexican-American Men's Fathering of Children with a Chronic Health Condition**

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Little is known about the challenges Mexican-American families face when their children have chronic health conditions. Although the entire family (mother, father, siblings, and extended members) may take an interest in a child, few studies have examined the effects a child with a chronic health condition has on the father from the father's viewpoint. Ten in-depth interviews of Mexican-American men were analyzed using a qualitative grounded theory approach to identify factors that influenced fatherhood among Mexican-American fathers with one or more children, 5 years of age and younger, with a chronic health condition. The analysis identified two major themes of *adjusting* and *taking care of business.* These two themes along with their supporting themes yielded the theory of *transformed fathering.* For these Mexican-American men, fatherhood meant not being absent, unconcerned, or solely a breadwinner and disciplinarian. Instead, they changed previous behaviors to convey more than a passive

presence in their child's life, a *process* of *transformed fathering*. This process is an involvement that displays an active participation in the child's life that fosters a healthy parent-child relationship. Implications for nursing, future research, and public policy are considered.

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# CHAPTER ONE

## INTRODUCTION

*Hispanic* is a broad term that describes people of Spanish and Latin descent. It is estimated that 37.4 million Americans are of Hispanic origin, making up 13% of the total U.S. population. Mexican-Americans are the largest and fastest growing, Hispanic ethnic group with an estimated population of 25.1 million or 67% of the Hispanic population (U.S. Census Bureau, 2002). Consequently, researchers in many disciplines have begun to focus on the unique concerns of Hispanics and, more specifically, Mexican-Americans. These disciplines include healthcare, psychology, sociology, and anthropology (Contreras, Kerns, Neal-Barnett, 2000; Gutmann, 1996; Rehm, 2000).

As a nurse, I have had the opportunity to work with many Mexican-American families, particularly those having children with chronic health conditions. In each case, I often observed that the caregiver at the child's bedside was the mother or grandmother, and I wondered if the father was involved in the care and how he might be affected by having a child with a chronic health condition. Upon inquiry, the mother would report that the father was working or had not been involved before or since the child's diagnosis. I began to ask myself a number of questions: How does a father's emotional and behavioral responses to his child's chronic health condition relate to the child's developmental outcome? How does the father's response or reaction affect family dynamics and acceptance of the child's health condition? Do healthcare workers have

stereotypical notions of Mexican-American men that circumvent their professional training to encourage fathers to become involved in their children's lives?

No parent anticipates the diagnosis that their child has a chronic health condition. When a child is injured or develops early symptoms, the diagnosis of a chronic health condition can shatter the parents' dreams and hopes. Moreover, the precarious nature of chronicity compels many parents to go through what Kubler-Ross (1969) describes as a process of internal and external responses of emotions to a catastrophic event. Consequently, the unknown outcomes of a chronic health condition can be devastating to parents. The readmittances to the hospital and the frequent visits to the physician's office are replays of the first time the parents heard "Your child has . . . ," whether cerebral palsy, sickle cell disease, AIDS/HIV, diabetes, cancer, or any of a variety of other conditions. In addition, the stressors inherent to caring for a child with a chronic health condition put strain on parenting and lead to unexpected role changes within the family structure (Heinzer, 1998; Ievers, Brown, Lambert, Hsu, Eckman, 1998). In short, the lives of the family members are drastically changed forever.

In her recent review of Latin American literature on fatherhood, Vigoya (2001) found that, for Mexican men, fatherhood represents the attainment of adult status and constitutes the most important experience in men's lives: "It inaugurates a public display of the complete, virile, and responsible man" (p. 239). Moreover, the Latin American literature has explored the variability of fatherhood as experienced by Latin American men of different socio-economic status, ethnic-racial allegiances, generational and

primary experiences, the specific moments of the life cycles in which they find themselves, and the sexes and ages of their children. However none of the literature in Vigoya's review examined Latin American fathers who had children with chronic health conditions. In fact, only a limited amount of research has examined the effects on fathers of having a child with a chronic health condition, especially Mexican-American fathers. Yet, the significance of the father's role in the care of such children is increasing, if only because of the increasing number of children with chronic health problems. The number of Hispanic children has increased faster than any other population group, growing from 9% of the child population in 1980 to 16% in 2000. By 2020, it is projected that one in five children will be of Hispanic origin (Federal Interagency Forum on Child and Family Statistics, 2002).

As nurses, we have the privilege of taking a personal, holistic approach to our work with families. In the hospital setting we admit patients; coordinate treatments and care with other hospital personnel; educate the parent and child on the chronic health condition, which includes treatments and possible outcomes; and discharge the patient. Among the healthcare providers, nurses have the greatest amount of contact with families; yet, somehow we have seldom included fathers in these activities. Because we see mothers as the central caregivers of children, in our research and in actual practice, we seem to have ignored fathers as participants in their children's care or even implied that their absence can be taken for granted.

How Mexican-American men define fatherhood could be quite different from the way other Hispanic men define it or from the traditional Eurocentric notion of the father's role. As of yet, we know little about the cultural, familial, societal, and personal expectations acting on Mexican-American men who are fathers of a child with a chronic health condition. It is important that nurses acquire that knowledge so that they can provide effacious interventions for the entire family. Although nursing research that focuses on Mexican-American men is scarce, healthcare researchers who study families caring for children with chronic health conditions have recruited research participants from diverse populations (Sterling, Peterson, & Weekes, 1997). This emphasis on cultural awareness and diversity reflects the growing appreciation among healthcare researchers that American society is less and less homogenous (Villarreal, 2004).

## Research Questions

The primary research question for this study is the following: What factors influence fatherhood among Mexican-American fathers who have a child with a chronic health condition? Specific questions are the following:

1. How do Mexican-American men define fatherhood?
2. How does having a child with a chronic health condition affect the dyadic relationship between father and child?
3. How does having a child with a chronic health condition affect the father's role in the family and his involvement with the child?

## Significance

For the past 20 or 30 years, sociologists, psychologists, and public-policy makers have researched the effects that fathers have on their children's development. Most research has focused on the negative effects of the absent or distant father on the behavioral, emotional, and psychological wellbeing of their families and children. Recently, however, interested public-policy makers and family researchers have attempted to define fatherhood, particularly responsible fathering and its effect on the family and more specifically on the child (Doherty, Kouneski, & Erickson, 1998; Marks & Dollahite, 2001; Parke, 1996; Pleck, 1997; Tamis-Lemonde & Caberera, 1999).

### *Defining Fatherhood*

Fatherhood has been studied by examining the type, quality, and quantity of involvement men have in their children's lives. In 1985, Lamb, Pleck, Charnov, and Levine described a framework that has guided research exploring the impact of father involvement in child developmental outcomes, examining how fathers were themselves fathered, and identifying specific predictors of father involvement with their children (Barnett & Baurch, 1987; Belsky, 1984; Bright & Williams, 1996; Eggebeen & Knosester, 2001; Halle, Moore, Greene, & LeMenestrel, 1998; Radin, 1982; Snarey, 1993; Volling & Belsky, 1991). Lamb et al. (1985) identified three key dimensions of father involvement: (1) *Engagement* (interaction) refers to the father's direct interaction with his child through caretaking and shared activities (e.g., play, diaper changing, and feeding). (2) *Availability* (accessibility) refers to the father's availability or potential

accessibility to the child. In other words, to what degree is the father available to the child, for example, by being present in the same room as the child, and to what degree is the child cognizant of his/her father's availability, whether or not direct interaction is occurring? (3) *Responsibility* refers to the amount of time the father spends with the children. Responsibility pertains to active participation in making the arrangements or providing the resources for the child. Examples of these activities include making arrangements for babysitting, setting appointments at the pediatrician's office and ensuring the child's arrival to these appointments, and determining when new clothes and shoes are needed. Other researchers have added to these three dimensions for assessing involvement. For example, Volling and Belsky (1991), in a summary measure of father-infant interactions, observed one-hour interactions that included the extent of "responsive, stimulating, and playful" interactions between father and infant.

Barnett and Baurch (1988) measured fathers' involvement in child-rearing activities in terms of quality and intensity. Five dimensions of father involvement were assessed: *interaction, solo interaction, proportional interaction, participation* (child care and household activities such as buying clothes), and *responsibility*. Parents were jointly asked to record the number of hours the father interacted with the child in various activities such as homework, playing games, and other child care tasks. This conceptualization of father involvement goes beyond tasks that are concerned with child developmental outcomes, but they include areas of involvement that directly effect the management of the household.

Radin (1982) developed a 23-item measurement scale that includes five dimensions of father involvement. Each subscale requires a report of the frequency and amount of time fathers are involved in specific childcare tasks, and each subscale score is based on separate responses from the mother and father: (a) an overall statement of involvement; (b) childcare responsibility, which includes feeding, bathing, dressing, and putting the child to bed; (c) socialization responsibility includes setting limits for the child's behavior, helping the child to learn, and disciplining the child; (d) influence in child-rearing decisions, which refers to parental decisions about when the child should be disciplined and when they are old enough to try new things, and (e) availability, that is, the frequency and degree that the father is in the home and available to the child for direct interaction if the child seeks it.

The above studies provide a basis for quantifying the involvement of fathers with their children, which is an important component of fatherhood. Most of the studies, however, are based on samples drawn from a majority White population, which limits the applicability of the findings to Hispanic-White and non-White men. Moreover, most of the studies examined the dimensions of fatherhood, as illustrated by Lamb, et al. (1985), but none specifically included fathers who had children with chronic health conditions. Finally, the studies did not address the dimensions reflecting the emotional, psychological, and cultural components that are often a part of an individual's decision to participate in activities. While it is true that Lamb and his colleague's initial assumptions have proved useful in an area of research where little is known, their framework fails to

address how a diversity of men define and experience fatherhood in the context of having a child with a chronic health condition.

*Responsible Fathering*

Doherty, Kouneski, and Erickson (1998) defined *fatherhood* as an "outcome of attitudes, meanings, beliefs, motivations, and behaviors" (p. 278) that ultimately determines responsible fathering and positive father involvement in a child's life. Walker and McGraw (2000) argue that the term "responsible" is value-laden, should not be based on gender specificity or the personal ideology of the researcher, and should be limited to empirically sound theoretical data. Doherty et al. (1998) concede that the existence of differences between children growing up with a father and children growing up without one does not necessarily mean that every child whose father is not involved meets with a negative developmental outcome nor that all children whose fathers remain involved develop normatively. In addition, research on fathers is not an attempt to marginalize or diminish the role of the mother in a child's life; rather, it is an attempt to shed light in an area of family research that has been understudied: men as responsible fathers.

Doherty et al. (1998) have attempted to reconceptualize fatherhood based on previous research that focused on the negative outcomes for children who are fatherless and identify the benefits that responsible fathering brings to women and children. According to Doherty et al., a responsible father is a man who waits to become a father until he is financially and emotionally capable of supporting the child; establishes paternity; and actively shares with the child's mother in the emotional, physical, and

financial care of the child from the time of pregnancy onward. This concept of fatherhood can be applied to all fathers regardless of ethnicity, social, or economic class and whether or not they reside in the home.

Popular culture has played a powerful role in promoting the renegotiations of family structure, thus changing the mindset of a generation. For example, the Eighties brought to television such programs as *Family Ties* and *The Cosby Show*. These shows were clear attempts to demonstrate visually the multidimensionality of responsible men. These "fictional" fathers were often depicted in situations where they had to make the critical choices of fatherhood, choices that would impact the lives of their children. They represented fathers living out lives as co-parents, significant role-companions, care providers, spouses, protectors, role models, moral guides, and teachers (Hanson & Bozett, 1991; Lamb, 1997; Volling & Belsky, 1991). "Only by considering the father's performance. . .and taking into account their relative importance in context, can evaluation of the father's impact on the child's development [be] legitimately analyzed" (Pleck, 1997, p. 25). It would be naïve to suggest that all families have the opportunities afforded the characters of these situation comedies. Nevertheless, the renegotiation of parental roles demonstrated in these programs reflected current societal trends, trends that included dual-earner households, women returning to school to pursue a career, and an increase in single-parent homes (Bennett, 2002; Fox & Bruce, 2001; Parke, 1996; Pleck, 1997).

Additionally, national and male-only social movements such as the *National Fatherhood Initiative, Promise Keepers, The Million Man March*, and *circulos de hombres* have encouraged men to place family relationships foremost, specifically their responsibilities as husbands and fathers: to honor women, men, and children (Bartkowski & Xu, 2000; Mena, 2000; Rodriguez, 1996). As Lamb (1997) points out, there is great importance in knowing the differences within and between groups of fathers if we are to understand fatherhood. For example, men who are of European descent may have a different view of fatherhood from that of men who are of Mexican descent. The essential need, therefore, is "empirical research that examines [fatherhood] in its cultural context, using representative samples of fathers to explore how cultural meanings and practices influence fathers' beliefs and behaviors" (Doherty, et al., 1998, p. 285).

## Research Problem

Mexican-Americans are becoming the fastest growing ethnic group within the Hispanic culture in the U.S. Within this group, children are facing chronic health conditions that have forced the nation to examine the current nutritional and ecological influences that impact their health. For example, there is a high prevalence of anencephaly and neural tube defects (e.g., spina bifida) within the Mexican-American population, especially those living in Texas counties bordering Mexico (Canfield, Annexes, Brenden, Cooper, & Greenberg, 1996). These conditions, usually recognized at birth, cause permanent and irreversible neurologic conditions. Furthermore there is a range of common chronic health conditions experienced by Mexican-American children;

such as Type II diabetes and obesity and asthma is the number one chronic health condition of all children younger than 17 years (CDC, 2001).

In a review of the current literature on fatherhood and children with chronic health conditions, Mu, Ma, Hwang, and Chao (2002) found that only a few studies in nursing reported differences between mother and father adaptations, roles, and parenting functions. Although fathers have unique concerns, there is little research addressing those needs as they relate to African American, Mexican-American, or low income fathers who have children with chronic health conditions (Dollahite et al. 1998; Hornby, 1994; Tamis-LeMonda & Cabrera, 1999; Marks & Dollahite, 2001). No argument appears in the literature that fathers, when faced with the challenge of caring for a child with a chronic health condition, experience greater concerns or have greater needs than mothers in the same circumstances.

Loving and caring for a child with a chronic health condition does not preclude any role for the father. Yet, nursing researchers have consistently overlooked the effects that caring for a child with a chronic health condition can have on the father and the effects that fathers have on these children.

> The failure to recognize that fathers are emotionally affected by the birth of a child with a chronic health condition not only deprives them of potentially helpful counseling and support but also conveys the implicit message that they do not matter and that they are not expected to behave or feel differently following a major family crisis (Pleck, 1997, p. 28).

Arguably, it is difficult to generalize about fathers whose children have chronic health conditions. Many factors can affect their experiences, such as the type of disability, the health and behavioral characteristics of the child, gender of the child, the fathers' education, economic status, personality, and interpersonal supports (Hamilton, 1977; Pleck, 1997). Ievers et al. (1998) explored family functioning and social support in the adaptation to the care of children with sickle cell syndromes. Of the 67 caregivers who were interviewed, 85% were mothers, 7% were fathers, and the others included grandparents and extended family members. Coffman (1983) conducted a study of parents who had children with cerebral palsy and their perception of parental needs and the needs of their children. Of the 203 parents studied, only 7% were fathers. The few studies that have examined the effects of father involvement in the care of their children with chronic health conditions have concluded that the more the father is involved, the less marital discord there is, the greater the father's confidence and competence in taking part in childcare activities, the more family cohesion there is, and the more the child's cognitive development is promoted (Chesler & Parry, 2001; Katz & Krulik, 1999; Young & Roopnarine, 1994).

## Theoretical Framework

Fatherhood is more than the biological event of fathering a child or the expectation to provide financial support to the family. Fatherhood encompasses the personal construction of identity for men. Fatherhood suggests an active participation in family life that promotes a healthy parent-child relationship. Harre (1984) would refer to

this construction as a personal philosophy that is one determinant for actions, reactions, and responses of an individual to any life event. The individual diverges from expected societal norms and conventional customs to develop his own identity. Gradually external influences like family, faith, community, environment, and culture are internalized in this process of identity formation.

The framework for this study is the theory of identity as outlined by Stryker's (1980) interpretation of symbolic interactionism and role theory. First, in Stryker's role theory, social positions are recognized as categories within the context of a social structure. These categories become symbols for the kind of person it is possible to be in a given society: father, student, professor, president, and so on. Therefore, the attachment of positional labels (role descriptions) to these roles directs society to expect certain behaviors from the individuals in those roles. The expected behaviors become symbolic of how society denies or accepts the role or position. More importantly, however, the actual behaviors depend on how the individual defines and organizes the role and thus interacts with society. Therefore by constructing his or her definition of a role, the individual forms an identity.

This ongoing development of personal identity can be explained by symbolic interactionism. Symbolic interactionism refers to a person's development as influenced by how he or she interacts with others and with the biological and environmental forces that shape the way one thinks and acts. Therefore, an individual is not passively socialized (Mead, 1934). Instead, all of the processes of socialization are predicated on

the individual's communications with others and interpretation of objects and their meanings through language and gestures. According to Mead, personal identity emerges from those social processes and the individual's interpretation of those processes. In other words, the self or personal identity is a reflection of ones understanding the immediate social milieu.

Stryker's identity theory encompasses the following: (a) persons are actors in as well as reactors to any particular situation, (b) a person's actions and interactions are shaped by the definitions and interpretations of the situations and interactions with others, (c) how a person defines him- or herself is critical to the process of producing action and interaction internally and externally, and (d) the perception of meaning is defined by interactions with others and the outcomes of the others' responses to that person (Stryker, 1991). Thus, Stryker suggests that individual actions are based both on the interdependence between self and society and on the self's independence in defining meaning (Stryker & Serpe, 1994). "Everyone is born into an ongoing social system of some sort and so looking first at the impact of society on the person is appropriate; however, the fundamental reciprocity of society and the person ought not to be forgotten" (Stryker, p. 53).

Stryker further asserts that the self is not only multifaceted, but it is also a hierarchically organized structure of identities based on commitment and role-choice behavior. This hierarchy is organized according to the individual's identity salience. *Identity salience* is the person's willingness to act out an identity according to the

meaning of the identity. That meaning, in turn, derives from the individual's interpretive cognitions. These cognitions, which are elements of knowledge and are therefore linked to attitudes, beliefs, and feelings about the self, provide a framework for interpreting and defining experiences. The individual embraces these experiences as consonant or dissonant in his salient role choices (Harmon-Jones, 2000). For example, a father who has a child with a chronic illness determines the salience of his role identities based on external influences. External influences include responses from the determination he resolves internally to make a choice and accepts the commitment and consequences of that choice.

Stryker's theoretical argument is designed to answer the question "Why does a person select one behavioral option over another in a given situation when both options are available to the person?" A version of that question, one more illustrative of the topic of the current study, is "Why does one father take his son to the park on a free Saturday afternoon while another opts to cycle with his buddies?" (Stryker, 1991). Stryker contends that "choice is a function of the relative salience of the identities to which the choices are related; the relative salience of identities is a function of commitment to the roles to which the identities are attached" (Stryker & Serpe, 1994, p. 24).

For example, a father who has a child with a chronic illness may reveal his commitment by talking about his child's activities (feedings, bathing, medication administration, physician visits, and so on) and his participation in those activities with coworkers and friends who do not have children. According to Stryker, such talk

indicates the salience of the fatherhood role to the man, demonstrates the positive dyadic relationship between the father and child, and shows how father-son interaction is affecting the man as a father. The father's commitment to participate in his child's physical therapy and night care takes priority over his choice to attend a basketball game with his coworkers. The consequence of this choice may be a drastically altered social life with the "guys," but the interaction also fosters a stronger relationship between the father and child. Therefore, the man must struggle between the *culture* of fatherhood—that is, the norms, values, and beliefs surrounding men as parents—and the *conduct* of fatherhood—that is, what fathers do, or their reactions, responses, and interpretations of internal and external symbols (LaRossa, 1997).

## Operational Definitions

For the purposes of this study, the following definitions are used: *Mexican-American* is any one who is a citizen or has legal residence in the United States and who is of Mexican birth or descent. *Fatherhood* is a broad term that embraces the father's attitudes, meanings, beliefs, motivations, and behaviors that shape his actions as a father toward his child (Doherty, et al., 1998). *Father involvement* is an active participation in the child's life that fosters a healthy parent-child relationship. The specific activities that promote the healthy relationship can only be observed and defined by the child and the father through their personal histories and experiences; however, for the purposes of this study, only fathers will be examined. *Chronic health conditions* is any condition that interferes with daily functioning for more than 3 months in a year, causes hospitalization

of more than 1 month in a year, or at time of diagnosis (Newacheck & Haflon, 1998). For the purposes of this study, a child with a chronic health condition will be less than 5 years of age.

## Assumptions

From my review of the literature on fatherhood throughout my doctoral program, from my synthesis of current published material for this study, and from my personal experience in clinical settings, I have made the following investigational assumptions:

1. Healthcare professionals do not sufficiently incorporate fathers, particularly Mexican-American fathers, in education and intervention programs for children with chronic health conditions.
2. Mexican-American fathers who have children with chronic health conditions express different or common concerns about their child, but in ways different from those of the mothers.
3. Mexican-American fathers want to participate in the lives of their children with chronic health conditions in responsible ways that promote a positive outcome for parents and children.
4. Mexican-American men want an opportunity to talk about their experiences as a father of a child who has a chronic health condition.

## Limitations

As an exploratory qualitative study, this study has the following limitations:

1. This study focused primarily on low- to middle-income Mexican-American families in which the mother and father reside in the home. Therefore, generalizability of the studies findings is limited.
2. In this study all children had been diagnosed with neurological deficits thereby limiting this study to children with cerebral palsy, Down's syndrome, and Autism.
3. This study did not include fathers of children with a terminal health condition.
4. All the participants in this study spoke English

## Conclusion

There has been little research regarding fathers who have children with chronic health conditions, especially Mexican-American fathers. Yet, fatherhood involves a personal and emotional investment whose rewards are shared by all stakeholders in the child's life (Doherty, et al, 1998). Exploring the experiences of Mexican-American fathers who have children with chronic health conditions will add important insights to the growing body of family research on fatherhood. The aim of this study, therefore, is to provide a deeper understanding of how these fathers make sense of their own actions and of the social world in which they live.

Townsend (2003) states, "cross-cultural evidence suggests that broadening the scope of inquiry beyond that which is considered typical from the dominant culture's

perspective can only enhance the researchers' senses to differences that may exist among and between cultural groups" (p. 274). Any indiscriminate acceptance of generalizations about fatherhood that ignore the differences among and between groups could easily limit the meaningfulness of research programs for those who have a stake in the issues. For example, the study of fathers in their actual social and cultural contexts may produce findings that contradict old, preconceived notions of Mexican-American fathers. Fatherhood in relation to children with a chronic health condition must be understood from the perspective of the participant. It is from that perspective, therefore, that this study attempts to build a new understanding of the meanings, the role choices, and the behaviors that infuse the role of fatherhood for Mexican-American fathers of children with chronic health conditions.

# CHAPTER TWO

## REVIEW OF LITERATURE

Events of the American past are the keys to understanding changes in the family of today. Events such as the Civil Rights Movement of the 1960s highlighted social injustice and reified equal rights through laws protecting ethnic groups and women. The Civil Rights Movement brought about changes through socially constructed events that forced governments at the federal, state, and local levels to alter hegemonic political, cultural, and social ideologies (Goldberg, 1993). For example, African Americans fought to receive equal access to public places and spaces and to ensure enforcement of their right to vote. Women fought for equal pay for the same jobs performed by men and the right to make decisions about their healthcare. Mexican farm workers wanted better working conditions, equality, and better economic opportunity. Other than the U.S. Civil War, no other movement in American history polarized race relations and equality more than the Civil Rights Movement of the 1960s. The reverberations of the Movement are still being felt today. Yet, some would argue that, while progress has certainly been made, there are areas of injustice that continue to affect these groups. One conclusion is plain, however: All these changes in the social and political arena have had profound effects on the American family.

Until the early 1960s, the middle-class family lived a traditional existence. The mother stayed at home to take care of the children, provide meals for the family, entertain guests, and clean the house. The father would go to work and financially support the

family. He would provide some discipline for the children; however, much of the household work and child rearing was left up to the mother. The father was considered distant in relation to family matters other than financial support (LaRossa, 1997). This paradigm was shattered by events beginning in the 1960s and continuing well into the 1970s. Increasingly in those years, families were challenged to renegotiate the family structure. A part of this need to renegotiate was a result of sudden increases in the number of women working outside the home, women going back to school to complete their education or acquire advanced degrees, and women delaying child bearing, as well as the increase in the number of single-parent homes (Griswald, 1993; Hanson & Bozett, 1991).

Even while the paradigm of the traditional family was shifting, however, families were still undergoing the stress from unanticipated health crises. Children, for instance, were still being diagnosed with illnesses or injuries that led to chronic health conditions. Such events continue to change family lives unequivocally and permanently. In those families, every member involved in the child's life undergoes behavioral, emotional, psychological, and physical adjustments. Moreover, the child may not be able to attend school regularly because of uncontrolled seizure activity. In that case, the child may experience a delay in the development of peer relationships, social interactions, cognitive development, and behavioral outcomes. Furthermore, working parents may have to modify their work schedules to accommodate the care responsibilities for the child, or they may have to work from home while managing physician visits and physical therapy

for the child. These awkward demands on the daily schedule can result in reduced or lost income and contribute to intrafamilial and marital stress as the family adapts to the increased healthcare needs of the child (Deatrick & Knafl, 1990).

While a considerable body of literature has addressed the effects of chronic health conditions on children and their families, little has focused on fathers, specifically minority fathers, who have children with chronic health conditions. The following literature review examines broadly the important research on the effects of chronic health conditions in children on the children's families and gives particular attention to Mexican-American families who have children with chronic health conditions.

## Chronic Health Conditions

A chronic health condition affects the individual on a physical, social, emotional, psychological, and spiritual level. Moreover, adaptation to the processes of managing symptoms and other demands of a chronic health condition affects all family members. Consequently, a nurse's approach to families who have children with chronic health conditions must be comprehensive. The nurse must understand the diversity, multiplicity, and complexity not only of the child's condition, but the ramifications the condition has on the family as a whole as well as the individual members (Corbin & Strauss, 1992).

According to Mishel (1995), a chronic health condition is a lived experience that can cause permanent variations in lifestyle that lead to the development of a variety of responses and demands for children and their families. Curtin (1995) states that "chronic [health conditions] are the irreversible presence, accumulation, or latency of disease

states or impairments that involve the total human environment for supportive care and self-care, maintenance of function, and prevention of further disability" (p. 6). Some characteristics of a chronic health condition are permanent impairments, nonreversible pathologic changes, residual disability, and rehabilitation, any of which may require long-term nursing management (Stephens, 1995). Chronic health conditions in children can include sickle cell disease, cancer, asthma, diabetes, obesity, cerebral palsy, and muscular dystrophy. Although some of these health conditions are more severe than others, they can entail permanent health damage or long-term rehabilitation that persists into adulthood.

Corbin and Strauss (1988) refer to the progression or course of a chronic health condition to its outcome as its trajectory. Some chronic conditions have a particular trajectory that is more predictable (e.g., cystic fibrosis), and that predictability assists the individual and family in planning and preparing for social events, transitions, or even death. Some chronic conditions, however, like sickle cell anemia or asthma, have unpredictable episodes, so that they involve fluctuating levels of uncertainty. This variability can "maximize personal and familial hardships" (p. 47). For the large part, therefore, the particular trajectory of a condition depends on the close cooperation of the affected individual, family members, and healthcare personnel as they collaborate to manage symptomatology and associated disabilities. This cooperative effort determines eventual outcomes (Corbin & Strauss, 1992).

*Children with Chronic Health Conditions and their Development*

Erikson and Piaget, two well-known developmental psychologists, identified markers for physicians, nurses, and parents to determine whether a typically developed child has reached particular psychosocial and cognitive milestones. These particular developmental markers can guide the assessment of a child's personality and intellectual maturity, which are dynamic throughout the child's lifespan. Moreover, developmental assessment tools that focus on the mental, physical, and emotional development of the infant and child, such as the Bayley Scales of Infant Development, can be used in determining the functional maturity of the child's intellectual development, learning, problem solving, and verbal communications skills, as well as the child's ability to sit and stand and to perform activities that require coordination of large muscles and fine motor skills (Kline & Bloom, 2003; Schnell, 1983). The assumption is made that behavior develops in regular patterns and is therefore predictable. This assumption is useful when one is assessing particular behavioral characteristics, such as the ages at which the child attains the motor coordination to hold up his or her head, sit, or walk (Boyle, 1983; Hamburg, 1983;).

In my experiences, children with severe chronic health conditions, however, may not attain the developmental milestones when expected for typical developmental processes. These developmental delays may further burden family functioning and require reconfiguration of family roles. The existence of the child's chronic health condition can modify parental expectations and aspirations for both their child and

themselves. For example, an infant who is born with cerebral palsy, depending on the severity of the disease, may not develop cognitively, physically, emotionally, and psychologically as a nonaffected child would develop. For example, a child with moderate to severe cerebral palsy may never peddle a bike, play football, eat without assistance, develop peer relationships, or speak coherently.

In an analysis of the National Health Interview Survey data from 1992 to 1994, Newacheck and Haflon, (1998) found that, from over 145,000 households, approximately 99,513 children had a chronic health condition. In that study, there was a 93% response rate for the years represented, and to alleviate the effects of inflation in the overall results, the researchers did not include children who were institutionalized as a result of their health condition. (The number of children institutionalized was about 0.14% of the total population of childhood chronic conditions.) According to Newacheck and Haflon's report, impairments of speech, spatial senses, and/or intelligence, mental and nervous system disorders and disease of the respiratory system were among the most prevalent chronic-condition categories restricting children's activities.

The earliest studies of children with chronic health conditions addressed medical treatments and included epidemiological studies that reflected the political and cultural currents of the time (Nikolic, 1968; Woolcock, & Blackburn, 1967). Recent research has included disease-specific medical treatments, management, and epidemiology (Abrams & O'Brien, 2004; Desrocher & Rovet, 2004; Reiff & Stein, 2003), quality of life (Bradlyn, 2004; Annett,. 2001), economic and financial impacts (Neff, Sharp, Muldoon,

Graham, & Meyers, 2004; Rehm, 2003), family influences and child adaptations to a chronic health condition (Claesson & Brodin, 2002; Deatrick & Knalf, 1990; Deatrick, Knafl, & Murphy-Moore, C. 1998; Knafl, & Deatrick, 1986; Ray, 2002; Rehm & Franck, 2000; Svavarsdottir & McCubbin, 1996), and an examination of diverse cultural and ethnic influences (Ievers, Brown, Lambert, Hsu, & Eckman, 1998; Rehm, 1999; Sterling, Peterson, & Weekes, 1997).

Along with the chronic conditions affecting the physical well-being of the child, families must also take into account the child's initial psychological, emotional, and behavioral adjustments. The level of adjustment or the effect the chronic health condition has on the child varies from individual to individual. According to Geist, Grdisa, and Otley (2003), one of the most powerful predictors of a child's adjustment and adaptation to a chronic health condition is how the family responds or reacts to the child and the chronic condition. Madden, Hastings, and Hoff (2002), in a study examining psychological adjustments in children with end stage renal disease, found that the severity of their illnesses did not affect the children's levels of adjustment. Instead, some of the themes that contributed to the children's adjustment to their renal disease included peer relationships, children's coping behaviors, and parental involvement and support.

Wolman, Resnick, Harris, and Blum (1994) used the concept of family connectedness as a measure of emotional well-being in children with chronic health conditions. Comparing adolescents with and without chronic health conditions ($n$ = 1683 and $n$ = 1650, respectively), the researchers found that a sense of emotional well-being

among the adolescents with chronic health conditions was highly related to the amount of family connectedness. Often, health care providers assume that families of children with chronic health conditions have a higher level of stress and dysfunction than families without a child with a chronic health condition. In a study using data from the Ontario Child Health Survey, Cadman, Rosenbaum, Boyle, and Offord (1991) randomly selected 1869 families. From these households, 3294 children ranging from 4 to 16 years of age were identified as either "being healthy" or "having a chronic health problem." The two groups were equivalent in terms of demographic characteristics. The study found that families with children who had a chronic health problem showed no greater family dysfunction than families who had children who were considered healthy. The researchers' conclusion was that families tend to move forward after their child's diagnosis and attempt to lead "normal" lives.

While the initial diagnosis of a chronic health condition causes families to reevaluate roles within the family and modify expectant child development outcomes, some families have made efforts, through a set of cognitive and behavioral processes, to manage and incorporate the child's care and needs into daily family routines (Rehm & Franck, 2000). Knalf and Deatrick (1986), in groundbreaking work with families of children who had chronic health conditions, identified the concept of normalization. *Normalization* within the family structure is defined as the process of acknowledging the chronic health condition, defining family life as normal, engaging in behaviors that

indicate normalcy of family life, and identifying the social consequences of the condition as minimal (Knalf & Deatrick, 1986).

In 1999, Deatrick, Knalf, and Murphy-Moore, revisited the concept of normalization and clarified the concept by integrating Robinson's (1993) concept of the "lens" that families use to define their sense of normalization when they have a child with a chronic health condition. With this added concept, Deatrick et al (1999) expanded normalization to constitute treatment regimens that are consistent with minimal disruptions of the child's and family's lives. This adaptation may modify certain prescribed treatments and make other adjustments as necessary to normalize family life.

The family-centered approach in pediatric health care includes all family members in the care for the child with a chronic health condition. The goal is to maximize the family's response as part of a healthy positive outcome. While these studies and others demonstrate the importance of normalization for a family and child to develop a sense of success in meeting the family's overall needs (Clarke-Steffen, 1997; Ray, 2002; Rehm & Franck, 2000), the above studies rarely include fathers, nor do they include samples diverse enough to yield generalizable results. Albeit, research on families and their children with chronic health conditions has begun to consider influences outside medical technology on the children's outcomes, the failure of researchers to recognize the impact of a child's diagnosis on the father lowers the perception of the father's worth in his child's life.

## Fatherhood

For the past 40 years many family researchers have focused their attention on fathers and fatherhood. The literature focuses on antecedents, consequences, and determinants of fatherhood (Flouri & Buchanan, 2003; Parke, 1996; Pleck, 1997; Woodworth, Belsky & Crnic, 1996); fatherhood and public policy (Halle, Moore, Greene & LeMenestrel, 1998; Tamis-Lemonde & Cabrera, 1999); how men were fathered (Eggenbeen & Knoester, 2001; Palkovitz, 2002; Parke, 1996); and the bidirectional effect of fatherhood on the child and fathers' adult development (Bright & Williams, 1996; Fagan & Iglesias, 1999; Lamb, 2002; Palkovitz, 2002; Snarey, 1993; Yogman, Kindlon, & Earls, 1995). Although studies about fathers and their children are few compared to mothers and their children, researchers have begun to examine the nuances of fathering among families of different ethnic and minority groups (Ahmeduzzaman & Roopnarine, 1992; McAdoo, 1993; Roopnarine & Ahmeduzzaman, 1993; Tamis-LaMonda & Cabrera, 1999; Townsend, 2002).

For this literature review, three areas were chosen for examination: father attachments and child development, fatherhood and male development, and fathers with children with chronic health conditions.

### *Father Attachments and Child Development*

Research on fatherhood and fathering has produced theory and concepts that have contributed to the notion that fatherhood is multifaceted and varied (Belsky, 1984; Doherty, Kouneski, & Erickson, 1998; Lamb, Pleck, Charnov, & Levine, 1985; Pleck,

1997; Stryker, 1980). The historic and landmark research conducted by Lamb (1975) challenged the abundance of research that up to that point concentrated on the mother-infant relationship as the sole predictor of an infant's secure and insecure attachments. According to Bowlby (1977), *attachment* is a "way of conceptualizing the propensity of human beings to make strong affectional bonds to particular others and of explaining the many forms of emotional distress and personality disturbance, including anxiety, anger, depression and emotional detachment, to which unwilling separation and loss give rise" (p. 201).

Attachment relationships have been classified into four categories: secure, resistant, avoidant, and disorganized. Secure attachments involve infants/children who utilize a caregiver as a base for exploration and, when confronted with distress, actively seek reassurance from the caregiver. Resistant attachments are demonstrated by the infant's/child's lack of exploration and the difficulty of separating from the primary figure. Avoidant behavior appears when the infant/child independently explores the environment and avoids contact with the primary caregiver but shows no avoidance of strangers. Disorganized behavior appears when the infant/child does not fit into any one of the above categories and exhibits contradictory behaviors. An example of disorganized behavior is contented play suddenly interrupted by extreme anger, or the child may display slow, incomplete movements or stilling behavior (e.g., like a deer caught in headlights; see Jacobvitz, 2002).

Bowlby emphasized the innate tendency for infants to connect emotionally and psychologically to a particular individual, who then becomes their principal attachment figure. Furthermore, this attachment relationship established at infancy "characterizes human beings from the cradle to the grave" (1977, p. 202). Focusing primarily on the mother-infant relationship, Bowlby suggested that maternal sensitivities determined how secure the infant's attachment behavior would be. Lamb, however, posited a number of questions regarding the father's role. Can infants have an attachment to fathers? Do fathers play an important role in the development of the child? Although Ainsworth (1982) and Bowlby suggested a hierarchy of attachment figures, the primary attachment in these hierarchies is to the mother.

In regard to a traditional nuclear family, Lamb (1975, 1981) argued that both mother and father play significant roles in the development of the child's secure attachments. Lamb's early assumption was not that fathers were more important than mothers in the developmental processes of their child, but that a sense of dual responsibility and accountability of mother and father was essential in developing a child's attachment behaviors (in this particular argument, Lamb did not address single-parent homes). Because of Lamb's critical analysis of the status of infant/child attachment theory, others began to look at the father's role in child development. Two overarching findings in the literature about a fathers' influence on a child's development were filtered out: the effects of the absent father and the effects of the involved father on the child's development, with the former receiving more attention. It became clear,

nevertheless, that fathers do have an impact on the development of the child (Bright & Williams, 1996; Yogman, Kindlon, & Earls, 1995). Whether the father resides inside or outside the home, his responses to his child can affect the development of the child on all levels.

In a longitudinal study conducted by Yogman, Kindlon, and Earls (1995), 985 low-birth-weight, premature infants (≤ 2500 grams; ≤ 37 weeks gestation) were followed from birth to 3 years of age. Although mostly children from low-income African American families, the sample included Whites and Hispanics from various socioeconomic backgrounds. Out of the 985 families, 16.2% ($n$ = 148) of the fathers were considered to have low involvement, which meant that they neither lived in the home nor had much contact with their child. The findings of the study showed that children who had involved fathers (residential or nonresidential), had higher cognitive scores on a standard intelligence test and the child's behavioral outcomes were positive, especially among African American families.

Bright and Williams (1996) studied nine African American fathers in a qualitative study that yielded four general themes: paternal beliefs and modes of functioning, strength and resiliency, racial socialization of children, and fathers as teachers in the home. Although the sample size of the study was small, the results suggested that fathers were important in the social development of their children and contributed to their education by reading to their children, assisting with homework, and encouraging their children to participate in school, which promoted scholastic success.

In a study conducted by Levy-Shiff, Hoffman, Levinger, Mogilner (1990), 50 preterm infants (25 males, 25 females) and their parents took part in a longitudinal study on father-infant relationships and infant development. All of these infants were preterm with the total average hospitalization of 63.2 days. Fathering and infant developmental data were collected during the hospital stay, at discharge, 8 months, and 18 months of age. The findings revealed significant correlations between the frequency of the father's hospital visits and the following: the father's confidence in caregiving tasks, such as diaper changing, holding, talking, and playing with the infant; the infant's weight gain; the father's later relationship with the infant; and positive psychosocial developmental outcomes of the infant during the first 18 months. While there is evidence that father involvement supports infant development, it is uncertain how much interaction (e.g. dose effect) and what type of interaction are needed to promote infant attachment to fathers. Most attachment theorists believe that attachment behaviors are established around 6 to 8 months of age. It is also believed, however, that play between the father and older child is instrumental in a child's social and emotional adaptations, intellectual development, and peer relationships (Parke, 1996).

*Fatherhood and Male Development*

In 1950, Erikson identified eight stages of human development, one of which is generativity versus stagnation. According to Erikson, generativity is essential to healthy adult development. Moreover, generativity implies that persons reach a plateau in their adult development when they have children. Palkovitz (2002) suggested that the male

developmental cycle is enhanced, and in some ways completed, when he becomes a father. According to Marks and Dollahite (2001), generativity in men who are fathers is depicted as responsible fathering that involves an "active, responsive involvement with one's child, working to meet her/his needs" (p. 626). This definition engages a moral capacity in the father (whether innate or learned) that compels him to respond to his child's need through means of his choosing rather than by role obligations imposed by structured ideologies (Chessler & Parry, 2001; Stryker, 1980).

Not being a father, however, does not imply that a man has not developed normatively. There are men who do not have children but who are nevertheless model citizens and have been generative in their work, philanthropy, mentoring of a child, coaching little league teams, and other contributions to society. In contrast, there are fathers who are physically present in their children's lives but have distanced themselves through work and adult activities that require no significant direct engagement with their children. Finally, there are absent fathers who abandoned their children and the mothers, providing little or no support for either (Palkovitz, 2002).

This latter type of behavior is an activity that is too real and frequent in our society to be ignored (Palkovitz, 2002). Bozett (1985), in his comparison analysis of male development and fathering, suggested that fathers continue to be self-centered primarily by setting priorities in three areas: clarification of their values, their beliefs, and their focus on occupational achievements. Furthermore, it is only when the child himself reaches adulthood that a more collegial relationship develops between that child and his

father, which suggests that the father's involvement is neither necessary nor sufficient in the adult man's development (Palkovitz, 2002).

Conversely, in his longitudinal study, Snarey (1993) used quantitative and qualitative methods to examine 240 men on parental generativity. These men participated in interviews at ages 25, 31, and 47. The quantitative ratings were limited to their first-born child; however, the fathers' descriptions of their participation in childrearing activities were obtained from self-reports and from their responses to open-ended questions. Six areas of the fathers' childrearing were examined: childhood social-emotional development, childhood intellectual-academic development, childhood physical-athletic development, adolescent social-emotional development, adolescent intellectual-academic development, and adolescent physical-athletic development. Snarey (1993) discovered that the active involvement of the father was determined by relationships (marital, relationship with their own father, and employment status). Moreover, neither the gender of the child nor the child's age affected the father's level of involvement. In this study, *father involvement* meant an emotional, behavioral, cognitive, and intellectual reciprocity between the father and his child. In addition, fathers described their own personal growth in response to their parenting.

> The actual dynamics by which parental generativity may promote fathers' personal maturity are, of course, very complex and not fully understood. Part of the process, however, seems to hinge on a father becoming bonded, committed to a child who periodically makes demands upon him which he

> is simply not prepared to meet. The resulting disequilibrium promotes the development of increased complexity in the father's cognitive, emotional, and behavioral repertoire in order to meet the basic needs of this one for whom he would willingly sacrifice all (p. 117).

Research has found that most fathers want to have greater involvement in their children's lives but are limited in how much they can participate because of societal demands and familial and cultural expectations. These may influence a man's transition to fatherhood; for example, they may affect a young father's confidence and ability in performing child care tasks such as changing a diaper, feeding, and bathing, and in providing the emotional and psychological support for his children (Ehrensaft, 1995; Hanson & Bozett, 1991; Palkovitz, 2002). Ehrensaft (1995) examined the shared parenting responsibilities among 40 heterosexual parents that the couples had agreed to prior to the birth of their first child. The findings indicated that fathers can be the primary caregivers of their children and accept responsibility for managing daily tasks such as diaper changing and feeding. Fathers, however, also described feeling inadequate about performing childcare tasks because the mothers expressed skepticism as to whether the fathers could complete tasks effectively.

The fathers' expressions of inadequacy are related to the persistence of gendered role expectancies of the mother, the father, and cultural and societal influences. Jordan (1995) conducted a study in which 30 couples (ages 21 to 47) were interviewed in regard to shared parenting responsibilities. These child-rearing responsibilities included bathing,

feeding, setting limits, and cognitive stimulation. Prior to becoming parents, these couples had envisioned shared responsibilities in caring for their children. Key themes in accomplishing role equity were time, flexibility, and commitment. Time included an equitable distribution of involvement, a willingness to be flexible, and a firm commitment to the role configurations each couple had established in relation to parenting. She found that while it was apparent that husbands could share the role of primary parent with their wives and participate in these tasks, the men were nervous about their performance, and women found it difficult to share parental and household tasks with fathers. Consequently, fathering became a reflection of the mother's beliefs, actions, and expectation of parental roles.

In contrast, Stryker would suggest that the action of the father is based on his choice to participate in the care of his child. Roles are interpreted and defined by existing symbols within the environment at an early age. This role interpretation shapes the role choice of the individual when he reaches adulthood. If a father wants to participate in roles that had once been gendered in relation to child care, he would define his involvement based on his past experiences, his sense of generativity, and his personal beliefs that have helped him become the father he is now and will be in the future. This process produces a set of identities that become salient. This process would counteract any actual or implied barriers a mother might demonstrate.

The examinations of gendered role behaviors, however, have focused on traditional role behaviors versus contemporary behavioral expectations. In fact,

discursions on gender-identity construction and traditional gendered role reconstruction have stimulated a great deal of new thinking. Connell (1995) suggests that identity is not "fixed in advance of social interaction, but constructed in interaction" (p. 35). Erikson (1959), in his analysis of human development, proposed that the essence of identity is based on synthesizing organized structures and processing interactions that have been role modeled and assimilated into one's consciousness. Chessler and Parry (2001) further state that gender identity is a product of historical, structural, cultural, and ideological forces that determine and reproduce socially constructed and shared understanding of what it means to be a man or woman.

Fatherhood and male identity development encompass a multitude of influences that invites constant unpacking and inspection. To analyze the relationship between male development and fatherhood, we need exploratory research designs that can examine the potential differences within and across groups. The goal of at least part of this examination is to gain a deeper understanding of fatherhood and male identity development from the perspectives of men who have children with chronic conditions and men from diverse cultural and ethnic backgrounds. Often studies in these areas focus on the negative aspects of men and fatherhood, and they derive mostly from White middle-class sources. Such studies seldom address the counterparts of these men in different ethnic, racial, cultural, and economic backgrounds (Marsiglio, Amato, Day, Lamb, 2000). As a result, there is a void in our knowledge of fathers who are positively involved in the lives of their children.

*Fathers of Children with Chronic Health Conditions*

Very little research has studied fathers who have children with chronic conditions. Hornby (1994) found that research on these children directed attention toward the mother and siblings, and little attention was given to fathers. The consistent focus on mothers who have children with chronic conditions is generally in acknowledgement of the mothers as primary caretakers, their easy accessibility as research participants, their responsiveness to family-oriented scientific inquiries, and their value as knowledgeable informants about their children's lives (Chesler & Parry, 2001).

In Clark and Miles (1999), a qualitative study conducted with fathers ($n$ =8) of children with congenital heart defects, however, fathers were found to have four interrelated conflicting reactions: joy in seeing the child born and in becoming a father, sadness and loss associated with the baby's illness, the challenge of becoming attached while dealing with fears about the infant's physical outcome, and the sense of a loss of control while trying to remain strong for others by hiding their intense emotions. While these feelings may not appear different than those the

mothers experience, the fact that few studies have attempted to acknowledge fathers' concerns about their children has become problematic in family research.

Marks and Dollahite (2001), in their study of Latter Day Saint fathers, found that spirituality and religion played an important role in the quality and quantity of a father's involvement in the life of a child who has a chronic condition. The guiding question of this qualitative study of 19 fathers was how meaningful and influential is religion

(religious community, religious practices, and religious beliefs) for fathers of children with chronic conditions. The outcomes of the study concluded that a father who held strong religious beliefs, observed religious practices, and who had a strong sense of community felt a sense of personal responsibility to be involved with his chronically ill children. This study did not present any comparison data; 17 of the men were Caucasian, and all were middle-income fathers. The study did, however, support the importance of familial connections and a sense of community that affect the father and how the father affects his external communities.

Bristol, Gallagher, and Schopler (1988) found that a father's acceptance or rejection of the child with a chronic health condition strongly affects the entire family. Their study examined spousal support and parental adaptation of mothers and fathers of developmentally disabled and nondisabled boys. The sample included 31 developmentally disabled and 25 non-disabled boys and their families. The study found a correlation between the amount of shared task involvement and expressive support, on one hand, and reduced depression, happier marriages, and better parenting, on the other hand. Although mothers of disabled children carried a disproportionately heavier burden than mothers with nondisabled children, father involvement in both sets was vital to the well-being of the family unit. Fathers who were especially involved with their disabled children were a critical source of support within the family.

Yet, Mu, Ma, Hwang, and Chao (2002) found few studies in nursing that examine differences between the mother and father in their adaptations, roles, and parenting

functions in regard to children who have chronic health conditions. Even fewer studies examine the nature of fatherhood specifically and their parenting roles with children who have chronic conditions (Chesler & Parry, 2001). Studies that have reported parental responses to children with chronic conditions show an unequal reporting of fathers' data or a reliance on mothers for reports about the fathers and their involvement in their children's lives (Ievers, et al, 1998; Rehm, 2000; Rehm, 1999; Seideman & Kleine, 1995).

In a comparison study conducted by Young and Roopnarine (1994), fathers' involvement in childcare, their marital stress levels, functioning styles, and support for childcare were examined among 47 families. The families were divided into two groups. One group comprised 23 two-parent families each with a child with a chronic condition, and the other group comprised 24 two-parent families each with a child who had no chronic condition. The average age of the children was 3.85 years. The chronic health conditions included Down's syndrome, autism, cerebral palsy, language or speech impediments/delays, and other physical disabilities. All participants were Anglo, well educated, and of middle income. The families with children who had chronic health conditions were enrolled in inclusive educational classrooms, and the children without a chronic condition were selected from preschool classrooms that did not serve chronically ill children. The study found no significant differences of father involvement between the two groups. The fathers participated in their children's care and were involved regardless of the presence of a chronic condition or not.

Katz and Krulik (1999) studied 160 families from Israel who were equally divided between those with healthy children and children with a chronic health condition. The research question involved whether or not father involvement with children who have chronic health conditions is different from father involvement with healthy children. They concluded that fathers with children who had a chronic illness experienced a greater degree of stress and expressed feelings of lower self-esteem. There was no difference, however, between the two sets of fathers in their amount of involvement with their children. The researchers used six questionnaires to study father involvement, but no qualitative data were reported, which would have brought insightful understanding to the study outcomes. These studies found no difference in the amount of father involvement as related to chronic condition or gender.

Hamilton (1977), in an analysis of fathers and children with chronic health conditions, concluded that a father's participation in his child's life is vital to family functioning. The father's involvement assists in reducing family stress, increasing family communication, maintaining discipline, sharing responsibilities, and achieving greater acceptance for the child within the family and in the greater community. Many fathers, moreover, have been found to respond generatively, remain involved, accept certain responsibilities, and become highly committed to their children with chronic conditions and to their families (Chesler & Parry, 2001; Dollahite, 1998; Katz & Krulik, 1999; Mu, Ma, Hwang, Chao, 2002).

## Mexican-American Families

Mexican-American families have been commonly described as large, cohesive, and patriarchal. Historically, descriptive studies of Mexican-American families reported that fathers had absolute supremacy in their families, while mothers practiced self-sacrifice, and in both cases their roles were defined by value orientations and perceived cultural norms (Diaz-Guerrero, 1955; Torres-Matrullo, 1976). An ethnographic study by Rubal (1966) in a Texas barrio concluded that respect for elders and for male authority were the two key components of the Mexican culture. Fathers were to be feared and respected regardless of the age of the child. The Mexican male and father have been portrayed as holding themselves proudly distant from other family members, except in the area of financial support and their authoritative dominance over the family. Actually, this early depiction of the patriarchal Mexican family was, and is, largely a myth. Such families have never been as common as once reported, and they are becoming even rarer in the face of modern social trends (Abalos, 1986; Cox & Monk, 1993; Mirande, 1991). Nevertheless, the old assumptions about Mexican men have contributed to sweeping generalizations in the research literature and have inhibited deeper explorations into the nature of Mexican-American men.

Even though vestiges of the dominant, patriarchal Mexican family man remain in the imaginations of some, feminist reinterpretations and critiques of past studies have made important contributions to our knowledge of actual Mexican-American families. These critiques have exposed the fallacies and caricatures of *machismo*, the qualities of

the hard-drinking, womanizing, tyrannical and dominant male, whose "manliness" precludes the domestic responsibilities of fatherhood (Brandis, 2002; Gutmann, 1997). These earlier descriptions of the Mexican-American family are what some would consider an ideology (patriarchy = pathology) of family life. Even so, male dominance and the strict adherence to gendered roles are slipping into Mexico's past, while urbanization, migration, and industrialization are transforming and redefining the identities of Mexican-American men and women (Cauce & Domenech-Rodriguez, 2002).

Four important trends have fundamentally changed the social context of the Mexican-American family structure: the increased participation of women in the work force, the decrease in nonresidential fathers, the increased involvement of fathers in intact families, and the exposure to greater cultural diversity in the United States (Cabrera, Tamis-LeMonde, Bradley, Hofferth, & Lamb, 2000). Among Mexican-American families, these trends include women working outside the home, thereby becoming important contributors to the family's overall socioeconomic status. As a result, the trends have subverted male dominance in some homes and granted women greater decision-making power. As a result, parental role choices and behaviors are more egalitarian than formerly purported (Baca-Zinn, 1982; Coltrane, Parks, Adams, 2004; Friedman, 1990; Rehm, 2000).

The construction of identity has been of interest among sociologists, psychologists, and anthropologists for some time. Many studies, however, have focused on generalized formations of identity, and recently some have begun to examine gender-

specific identity formations, for example, masculine identities and their effects on families and children (Brandth & Kvande, 1998; Bozett, 1985; Palkovitz, 2002). Yet, there remains a lack of investigations into male identities in the context of culture and ethnic identity construction. Consequently, unsupported generalizations may arise that can be attributed only to the expectations of the dominant culture and its structural influences, while the generalizations may not reflect reality at all (Connell, 1995; Hanson & Bozett, 1991; Townsend, 2002). For example, Mexican-American males are depicted as "typically" *machismo,* while clearly many Mexican-American males refuse to subscribe to such role expectations.

Moreover, contemporary efforts have attempted to examine, explore, and redefine *machismo* from anthropological, feminist, and sociological perspectives of male identity construction. From these perspectives, male identities (masculinities) are defined by a set of attitudes, behaviors, emotions, feelings, beliefs, and values that are socially and culturally constructed by multidimensional processes that are fluid, nuanced, and shaped by gender relations, culture, and structural influences on men and women (Gonzalez-Lopez, 2004). *Machismo* today is being redefined as a term applying to men who involve themselves in all aspects of their children's lives, feel a respect for women in more egalitarian roles in and outside the home, exercise moderation in their use of alcohol, and persevere as the husband of one wife (Rodriguez, 1996). The contemporary representation of the Mexican-American male identity is past the point of the progenitive event, and it is directed at "what men say and do ***to be*** *men* and not simply on what men

say and do" (Gutmann, 1997, p. 17 ). Clearly, attempts are being made to deconstruct a myth into realistic observances .

*Mexican-American Families with Children who have Chronic Health Conditions*

Mexican-Americans are the largest ethnic group within the Hispanic population, comprising 66%. Mexican-Americans are more likely than non-Hispanic Whites to live predominantly in or immediately surrounding the downtown areas of large cities (urban inner cities), and they are more likely to live in households with more than five family members. Of their total number, 35.7% (compared to 23.5% of non-Hispanic Whites) are younger than 18 years, and they have lower levels of education and higher levels of unemployment and poverty (Therrin & Ramariz, 2000). According to parents' reports, however, 73% of Mexican-American children are in excellent to very good health, although few receive annual physical exams (National Health Interview Survey, 2002).

Little is known about the challenges Mexican-American families face when their children have chronic health conditions. Although the entire family (mother, father, siblings, and extended members) may take an interest in a child with a chronic condition, few studies have examined the effects a child with a chronic health condition has on a Mexican-American family. Flores, Abreu, Olivar, and Kastner (1998) reported that, while the lack of insurance and financial difficulties are important, they are not the only factors that limit Mexican-American parents from accessing health care for their children. These parents identified the inability to speak English adequately and the long waiting periods in clinics and doctors offices, as well as the lack of medical insurance and the difficulty

paying bills, as the most important barriers in seeking medical assistance for their children.

In a study of 25 Mexican-American parents and their experiences with childhood chronic illness (Rehm, 1999), six dimensions of faith were identified as moderating effects of decision making and parental caretaking. These six dimensions were that the outcome of the child's illness was up to God, the close relationship between God and medical care, the parents responsibility to "call on God" for help, the continued obligation to maintain religious practice during and after their child's illness, third-party intercession to God on behalf of the family, and faith-encouraged optimism. Their religious and spiritual beliefs were "powerful in assuring their child's recovery and stability" (p. 37).

Rehm (2000) used the same sample as above to explore intrafamilial relationships with Mexican-American families who had children with chronic health conditions. She found that these parents were active in their child's care, where their focus was to encourage, protect, and advocate on their child's behalf in relation to health care services. These two studies refuted stereotypical notions of fatalism depicting parents sense that the outcome was neither predetermined nor unalterable. Passivity in regard to the health care of a child with a chronic condition was not an option among these Mexican-American families. Fathers, however, continued to be minimally represented in the study (N= 5 fathers and 19 mothers).

Mardiros (1989) found that Mexican-American families attempted to make the child with the chronic condition feel as much a part of the family as their other more typically developed children. Families utilized spiritual and religious practices to "see them through" the child's condition, and they reported a more cohesive relationship with other family members and their spouses. In this ethnographic study, Mardiros concentrated on the cultural and societal expectations of normalized behaviors in order for a child with a chronic condition to be accepted within the community. These studies have provided an introductory insight into a population that has received little attention. However, a deeper understanding of the individual family members and the effects of culture, identity, structural influences, and personal philosophies is needed to discern the relationship of the individual to the family-unit imperatives.

To summarize, the literature presented in this review includes quantitative and qualitative research findings from studies of families who have children with chronic health conditions, of Mexican-American families, fathers with children with chronic health conditions, and children with chronic health conditions in Mexican-American families. It is imperative that nurse researchers focus on Mexican-American families because Mexican-Americans are rapidly becoming the largest ethnic minority group in America. More importantly, there is a great need to learn about family dynamics and fathering in families in which there is a child who has a chronic health condition. In particular, little research has focused on Mexican-American families who have children

with chronic health conditions, and even less is known about the roles of the fathers in those families. The study is intended to fill that gap in knowledge.

# CHAPTER THREE

# METHODOLOGY

The focal point of this chapter is to describe the research method and design used to conduct this study. It includes a description of the proposed and actual sample, procedures for data analysis, and measures for testing the trustworthiness of the theory. Most of the information given in this chapter was reconstructed from my personal research journal, field notes and anecdotal notes made during interviews. This journal was written in long hand and is secure in a locked file cabinet with other research material related to this study.

## In the Beginning

According to Denzin and Lincoln (1998), qualitative research involves the use of "empirical matters—case study, personal experience, introspective, life story, interview, observational, historical, interactional, and visuals texts—that depict routine and problematic moments and meanings in individuals' lives" (p. 2). One method of qualitative research is grounded theory that is philosophically based on symbolic interactionism. In the grounded-theory approach, the researcher continually compares data collected from diverse sources (observations, artifacts, interviews), identifies categories as they emerge from the data, and eventually constructs a theory to explain the relationships among the categories and to describe the phenomenon under study (Glaser & Strauss, 1967). While grounded theory provides a rigorous approach to the study of a

broad range of human issues, it makes its greatest contribution to scientific research in fields where little is already known.

Grounded theory is particularly suited for nursing research that seeks to explore systematically long ignored or overlooked population groups and to identify the social and cultural forces acting on those groups. Such research is essential to the provision of clinical practice, and to the design and implementation of viable health-promotion programs that might benefit those groups and their communities. In this study, therefore, grounded theory was implemented to examine the experience of fatherhood among Mexican-American men who have children with chronic health conditions, that is, to explore what fatherhood meant to those men, how that meaning was affected by the health of their children, and what factors influenced their roles as fathers.

*Sample and Setting*

Participants in this study were Mexican-American fathers who had one child with a chronic health condition. I initially set about contacting multiple agencies in Austin and San Antonio that accommodated families and their children with chronic health conditions under the age of five. After several months of attempted contacts via telephone and email with several different agencies, it became apparent that one agency would provide a majority of my participants for this study. Most of the participants were recommended from an Early Childhood Intervention program located in San Antonio. Two fathers were contacted through a program facility in Austin.

Since this target group has received little research attention, I had anticipated interviewing approximately 20 fathers, each of whom had a child with a chronic health condition such as asthma, cerebral palsy, cystic fibrosis, and diabetes. However, because I had reached saturation and faced issues during the recruitment process, I was able to interviewed 10 fathers whose child had the following chronic health conditions: cerebral palsy, Down's syndrome, and Autism. The initial interview and follow-up interviews took place in their homes, businesses, or other mutually agreed upon public places. Eight fathers met me in their homes. The mother of the child was either in the same room or in a separate room within the home during these interviews

*Eligibility Requirements*

To take part in this study, participants met several eligibility requirements. They were over 18 years of age; agreed to participate in a 1-hour face-to-face interview; and were available for follow-up interviews. Most importantly, they had to be: (1) Fathers of children who had a chronic health condition. I did not specify the type of chronic health condition children had to have in order for their father to participate in the study. I had operationally defined a child's chronic health condition as any condition that interferes with daily functioning for more than 3 months in a year, causes hospitalization of more than 1 month in a year, or at time of diagnosis (Newacheck & Haflon, 1998). (2) Self-identify as being of Mexican-American ethnic origin. Although I had made advanced preparations and had available a Spanish translator to accompany me to each interview, each father was able to read, write, speak and understand English. (3) A resident in the

United States for at least 5 years. I chose this residence criterion for Mexican-American fathers because, according to an expert on Mexican-American immigrant families, a 5-year period of permanent residence in the United States suggests that the family intends to remain in the United States (Gloria Gonzalez-Lopez, personal communication, 2002). I did not interview any father whose child had a chronic condition that was terminal. The reason for this exclusionary criterion was that such a father would be experiencing a dimension of fatherhood beyond the scope of this study.

*Recruitment Procedure*

When I first began my recruitment of fathers to participate in the study, those in the community met me with mixed support. Those who were negative about the project responded to one facet about Mexican-American culture that is often associated and misunderstood: machismo. Consequently, before I begin to present my recruitment strategies, I would like to spend some time addressing this phenomenon that is frequently associated with Mexican-American male identity, particularly the identity of fatherhood.

I identified social workers and case managers as gatekeepers to this specific population of families. For that reason, after speaking briefly over the phone, I made an appointment with a social worker who worked at an agency that provided services to families and their children who had various chronic health conditions. After explaining my project in total and my request for her assistance in the recruitment process, her first comments to me that I wrote in my field notes were the following:

> Oh you will never get enough men to participate in your study, they are either not in the home, not with the mother of the child anymore, or they just don't care. You know how Mexican men are…you know they are macho…they see that child as a negative of their manhood…they don't what to have anything to do with the child and they blame the mother for having a baby that is not perfect…especially if it is a male child…good luck.

This statement reflected the sentiments of some in the community. Although I understand that this particular social worker was voicing her opinion, I believe she represented concerns of several who had worked with families who had a child with a chronic health condition. I was disappointed and frustrated with the sweeping implications and ramifications of this social worker's statement. Because of this mind-set, I believe that my recruitment strategies may have been unintentionally undermined.

Gutmann (1996) explored the dominant ideology of the Mexican man. He stated, "…widely accepted generalizations about male gender identities in Mexico often seemed egregious stereotypes about machismo, the supposed culture trait of Mexican men that is at once so famous and yet so thoroughly unknown" (p. 12). While Gutmann's study focused on male identities in the Mexican state of Santo Domingo, Mexico, the cultural trait and the preconceived generalized stereotyped notions of what is machismo is perpetuated about Mexican-American men in the United States as well. This is not to say that some negative products of machismo often associated with Mexican-American men are non-existent. However, is machismo relegated only to Mexican-American men, or to

only one gender? Truly, the subordination and domination of women by men exists in some Mexican-American households however, "the notion of a unitary maleness, whether conceived of as national or universal in character, is wrong and harmful" (Gutmann, 1996, p. 21).

Knowing that more of the same attitude and beliefs may confront me, I continued to pursue my original plan of recruitment. I utilized a form of convenience sampling called nominative (snowball sampling). I provided a cover letter/flyer (Appendix B) to friends, family, and coworkers in order to initiate recruitment for potential participants. After 8-12 weeks of continuing this strategy with no positive results, I decided to implement another strategy of contacting multiple agencies in and around the Austin and San Antonio community. These agencies worked with families and their children who had chronic health conditions and who were under the age of five. I initiated contact by introducing myself through phone conversations with program directors. After each telephone conversation, I was assured that means were in place and possibilities existed to assist me in obtaining potential participants for my study. I thought this initial approach would elicit an invitation to meet, however, telephone communication seemed to be the most convenient form of contact and proved to be the least time consuming for them. These program directors asked me to send information regarding my project by means of email. While the telephone conversations were positive, 6-8 weeks of none or little follow-up contact in regards to potential participants, I decided to employ another recruitment strategy.

I became more assertive and made appointments for face-to-face meetings with different program directors of early childhood programs, especially those who worked with families and children with chronic health conditions. After contacting several agencies and meeting face-to-face with several program directors, I was able to present my project at an Early Childhood Intervention Program. I was given permission to speak 10-15 minutes to approximately 30-40 social workers and case managers who dealt directly with families and children who met the criteria for my study.

I originally thought most of my recruitment would occur through the fathers. In other words, two or three fathers who met the inclusion criteria would know other fathers who might be possible candidates for the study. I thought this method would not only help me to obtain my desired sample size (Polit & Hungler, 1995), but indirectly each father would meet other fathers, and in some informal way, a network of support could be started. However, none of the fathers expressed knowing other fathers who had children with a chronic health conditions or being a part of a support group. All of my participants were recruited through social workers or a case manager. They sought and received permission from the fathers to release their names, telephone numbers, and addresses to me. For those fathers who granted permission, I contacted them by telephone to set up an interview time that was convenient for them. When I met with the fathers, I introduced myself, explained the study to the fathers, answered their questions and obtained their signature on a written consent form. Pseudonyms were given to each father and their

child. Since all the participants wrote and spoke English fluently, I did not have to use an interpreter.

## Data Collection

Over the course of one year, I spent 25 hours interviewing participants. The majority of data collection took place in weekend meetings. While my participants were not compensated, at periodic intervals I would send updates of where I was in terms of completing the study. In this section, I would like to present an overview of my theoretical sampling and coding process.

### *Participant Demographics*

After each father gave his consent (Appendix C) to participate in the study, demographic information (Appendix D) was obtained prior to the beginning of each interview. The age of the fathers who were interviewed during this study ranged from 24 to 48 years, with an average age of 35.8 (N=10). All fathers were of Mexican-American descent. Eight of the 10 fathers worked full-time outside the home while two were stay-at-home fathers. Two of the fathers held Bachelor degrees, two had Associate Degrees, two had some college hours, two had completed high school graduate, and two had completed technical training. The number of children each father had ranged from one to five, with an average of 2.5 children. Nine out of ten fathers were married to the mother of their children. Two were living with the mother of their child and one father was divorced from the mother of his child. All of the children had a chronic health condition

that met the inclusion criteria, including six with Cerebral Palsy, two with Downs Syndrome, two with Autism.

*Theoretical Sampling*

Theoretical sampling begins at the inception of data collection. A grounded theory approach utilizes a research methodology that invokes an engagement between the data and the researcher. This engagement is a *meshing* of information that mirrors the continual process of experiencing the data at numerous times, places, and in various ways finding relationships between themes or codes. Constantly comparing data through an analytic process whereby codes are identified and "further theoretically developed with respect to their various properties and their connections with other codes until saturated" (Glaser, 1978, p. 36). Consequently, a theory is extracted based on the relevance and "fit" of a basic social process that provides meaning, insight, and increasing understanding of a little known phenomenon (Glaser, 1978; Marshall & Rossman, 1995).

I started collecting data when I arrived at the mutually agreed upon place for the interview. I made mental notes of the environment and frequently met the spouse or other children prior to settling into the interview with the father. I made observations of each father's body language and responses to me. Because the fathers were recruited using a nominative sampling approach, I made sure the fathers knew the exact purpose of the interview and a little of my professional background. I was determined to try to make these men as comfortable as possible about and during the interview.

I used a semi-structured interview guide (Appendix E) to conduct interviews with each father. The interview guide gave me a framework for initiating a conversation with the father. During data analysis, the interview guide was adapted by adding questions or probes to address emerging concepts. Moreover, the interview guide helped to ensure that I covered all relevant topics, while allowing the father to talk freely about his experiences. The interview guide allowed me to change my interview style to meet eventualities, to facilitate the flow of ideas (Polit & Hungler, 1995), to identify and explore new topics that may have emerged during the interview.

After the first interview and subsequent interviews, I made field notes and kept a journal. I utilized my field notes to reconstruct interviews and my observations while they were fresh in my mind. After each transcribed interview was returned to me, I would listen to the audio-taped interview, compare the transcript with my field notes to refresh my mind about the interview, check for accuracy in the transcription, fill in blanks in the transcription that were unclear to the transcriber, and begin analyzing and coding the data.

I recruited a transcriber before my initial interviews began; but she was unable to fulfill her commitment in a timely manner. Consequently, I had to advertise for and recruit another transcriber. After several weeks of advertising, I found a qualified transcriber, who was able to transcribe the interviews shortly (e.g. within 1 to 2 weeks maximum) after each interview took place. As I coded transcripts and re-read my field

notes, I wrote memos that identified codes, questions, insights, and connections within and between the data.

Throughout the reading of the transcripts and coding of data, memos were very helpful in providing directional thought. It was common for my memos to change as I continued to ask myself questions about the emerging substantial codes, saturation, and comparisons. The following is a memo that reflects my thoughts about and eventually one of the supporting codes of the theme *taking care of business*:

> 10/03/05 I think Clare and specifically her illness has in some or many ways changed his perspective of fatherhood. The term "being there" has come up repeatedly. The definition he lends to this concept now is different from with his other kids.
>
> 07/06 I noticed with Mr. Ramiriz, he is defining or listing behaviors that are similar to the concept of "being there". Most of the fathers either have used this term or have delineated potential properties of this concept.

As data collection progressed, I was able to recognize salient theoretical and conceptual categories that were emerging. I quickly recognized the importance of maintaining a constant presence with the data and devoted 24 hours a week over a period of six months, to analyze collected data. After some time, I realized the importance of seclusion and embedding myself in the data prior to the next interview. Once I was able to devote focused time to this process, I began to notice redundancy among initial codes and concepts. In other words, I began to reach saturation, in which a theory or set of

hypothesis was nearing a completed composition (Glaser & Strauss, 1967). However, because of the contingent nature of qualitative study and its methods, I asked each father if I could have a second interview if deemed necessary during the analysis phase of the study.

## Data Analysis

Grounded theory requires a constant and systematic comparison of data as it is collected. The result of this ongoing comparison is the utilization of simultaneous coding and analysis "in generating a theory that is integrated, consistent, plausible, and close to the data…" (Glaser & Strasuss, 1967, p. 103). The initial phase described will be theoretical coding which is essential in the identification and extraction of abstract categories and themes

### *Theoretical Coding*

As I read over each transcript while simultaneously listening to the audiotaped version, I had to keep in mind three important questions as I was beginning and throughout this process of coding the data.

1. What is this data telling me?
2. What category does this incident indicate?
3. What is actually happening in the data?

These were questions that Glaser (1978) deemed essential in governing open coding of the data. Remembering some of the events the fathers recounted, their verbal cues, facial expressions, and emotional responses became poignant moments for me. The interview

data itself and the process of analysis, at times felt overwhelming. However, the importance of this project for science and practice helped me persevere. Moreover, each father displayed assurances of how important it was to get this information to healthcare workers and so I pressed forward.

Glaser (1978) states:

> The analyst codes for as many categories that might fit; he [sic] codes different incidences into as many categories as possible. New categories emerge and new incidences fit existing categories. He [sic] may even code for what is not obviously stated. This maximizes allowing the best fits, the most workable ones and the core relevancies to emerge on their own (p. 56).

I initially began the analysis process by re-reading every transcript line by line coding for words or phrases that I thought plausible in the formation of categories. I would then place the coded information in parentheses near the sentence or phrase I was coding. For example:

> Interviewee: Oh, gosh, ah. First realizing, ah, that there's special needs {prefers the term special needs v. chronic health condition} that we need to adjust {adjustments} because we can't take for granted that at the age of five, now, that he can up and walk and do some of the things like feed himself.{realization of child's limitations, or his abilities}

I did not know whether these codes were relevant or not. In fact, I would not know until I had reached a saturation of the data. However, this line-by-line approach

helped me to focus, listen closely to what the fathers were saying and how they were saying it. Line-by-line coding allowed me to compare and identify relationships between codes and emerging categories. Admittedly, this line-by-line approach was time consuming. Quite often, I would set down one interview not to examine another for several days. I had to remember not to insinuate my own ideas or theoretical conclusions into the data. My approach of stepping away from the data for a few days gave me some clarity and refocused my efforts.

After about six interviews, I then moved toward selective coding in which "the analyst delimits his coding to only those themes that relate to the core theme in sufficiently significant ways to be used in a parsimonious theory" (Glaser, 1978, 61). Consequently, I began to realize that a central category or theme was evolving from the data. Capturing the essence of the central theme was challenging. I attempted not to partition other themes that might be central or become co-central themes. Once I had committed to the notion that the basic social process for these fathers is related to behavior and cognitive processes transformed by an unexpected event, then the evidence to support the core theme of *transformed fathering* emerged.

*Comparing Incidents*

Comparative analysis of the data is very important in grounded theory. There are four stages utilized during this process "1). comparing incidents applicable to each category, 2). integrating categories and their properties, 3). delimiting the theory, and 4).writing the theory" (Glaser & Strauss, 1967. p. 105).

I read each interview going line by line to discover codes that I believed essential in discovery. I made notes in the margins of each transcribed interview. These consisted of more questions or codes. After the first two interviews, I began to search and examine the data I had collected up to this point for comparison. I looked for similarities and differences in identified codes across the data. I attempted to keep in the front of my mind "What does this indicate?" I did not always use gerunds during the discovery process while coding the data.

I also tried to use descriptive words that the fathers used during their interview. For example, one father stated, "And it was horrible because like feeding her. We were so, I was so afraid to just handle her…" The code applied in the margin for this interaction between father and child was *fear.* Later I found it somewhat difficult to identify gerunds that captured the fundamental nature of the data collected. This became somewhat frustrating for me. Consequently, supporting categories, themes and core theme names changed often. Once I identified supporting categories and themes, I continued to make memos at various points within and between each interview.

Using a word processor, I developed documents with columns and labeled each one according to the transcripts. After gathering multiple codes, I began to collapse similar codes and place them under emerged categories. After comparing the categories, I realized that some of the categories where similar and began to collapse similar categories. Once this was completed, I began to notice themes emerging and identified supporting categories of the themes.

*Integrating Categories and Their Properties*

As Glaser (1978) stated, "Memos are the theorizing write-up of ideas about codes and their relationships as they strike the analyst while coding" (p. 83). Memos were recorded often throughout interviews. These memos often included questions and provided definitions to coded words or categories. Memos provided ideas for further questioning of the data and eventually provided a means of integrating codes and themes in order to generate theory or a set of hypothesis (Glaser, 1978). For example, the following is a memo identifying similar thoughts between the data that created the supporting category of *uncertainty*:

> 06/06 Uncertainty has several characteristics as defined by each father: what others have described to these fathers about their child's chronic health conditions, his experiences with his child's condition, his anticipation of what his child may need in the future, and financial concerns (related to the child: healthcare cost, educational cost, therapies).

I also wrote about properties of supporting categories. I identified the relationships and linkages between codes and categories. The following is an example of initial linkages among supporting categories and their properties:

> 10/06 I am seeing a connection between *absorbing information and seeking answers*. These two categories are related to *uncertainty.* When these fathers were confronted with an unknown health concern related to their child, the uncertain financial burdens, healthcare concerns, and long-term needs, they begin seeking

answers to all things related to their child's condition. This information was sought from many sources (family, friends, health care workers, and the internet). Time allowed the fathers to absorb the information. Although they had this information they continued to have a certain level of uncertainty.

*Substantive Theory*

I did not begin searching for a core theme at the beginning of analysis. Admittedly, I believe that I had some preconceived notion of what the outcome of the analysis would elicit. After each interview, I felt that these fathers were chipping away at preconceived stereotypes of what a father should be, particularly what or how Mexican-American fathering is defined. I continually reminded myself that it was for these men to tell their story, for the data to speak for itself. However, I was also aware of my first introduction to the social worker had been. I did not want her comments or actions of others to prejudice my approach to this project or to limit my awareness of what the data was telling me. Consequently, I had to set aside the data for several weeks in order to rethink my approaches to how I was looking at the data. After several weeks of setting aside the data, self-reflection, and debriefings with a colleague, I was able to pick up the data and proceed to code with fresh eyes.

Initially, I felt that a core theme would emerge during my data collection and analysis process. During this process, intuitively and supported by evidence I began to recognize several core themes. At first, I thought the core theme was *uncertainty and gathering information.* However, after several more interviews and further data analysis

the concept of *being there* began to sum up what fatherhood meant to these men and I thought it was the core theme. With continued emersion in the data, I begin to see what Glaser (1978) states as the "main concern or problem for the people in the setting" (p. 94). The "main concern" as Glaser describes it became clearer to me, and the core theme was identified as *transformed fathering*. While the previously mentioned concepts became themes, or supporting categories, and properties, *transformed fathering* was established through data analysis as the core theme. I believe this concept illustrates a cohesive relationship between the themes and supporting categories and became the best fit for data interpretation.

Using my word processor, I placed each code identified in the data analysis in columns labeled by the father's pseudonym and interview number. I identified supporting categories by grouping like codes. Each father's interview was color coded. Each code corresponded to the color coded interview. Each code was also given the line number of where it was found in the original interview transcript. This was done for ease of indexing and sorting the data. Subsequently, each related code was grouped together for similarity. Once completed, these codes were placed under the headings of supporting categories which become defining properties of emerging themes.

Field notes were checked often for verification of coding. If there were differences noted in the field notes and what I had initially coded, I placed a memo of the incident to describe how it related to existing themes and their properties. I wanted to make sure that what was written in my field notes, to the best of my ability, represented

what was in the coded data. After several weeks of continued comparisons, I believed that I had reached a point of saturation and went back through the interviews to sort my memos.

*Writing the Theory*

This is the final stage or end result of the constant comparison of data. This can also be the most difficult. I did not utilize any type of computer program specific to qualitative research, such as NUD·IST, for indexing the data or during the data analysis. I developed tables to manage data, supporting categories, and themes using a word processor and excel spreadsheet. All codes were written out in the margins of the transcripts in long hand. All memos were initially written long hand when replaying the audiotapes and reviewing transcripts. I then transferred those memos within the body of the transcripts that were word-processed. These memos were given a different color font for identification and sorting. The font color for the memos matched the color font of the participant and codes. I cut and pasted memoed information in a word-processed document, which served as secondary level of sorting and enhancing theoretical integration. I continued to refer to interview data to validate that these memos were based on the evidence of the data and not my own imagination.

I found that after sorting through my memos and field notes, I needed another method in order to visualize and to help me in the process of successfully writing the theory. As a result, I placed large white butcher paper across a wall. At moments my codes, supporting categories and themes were placed on it. Eventually a diagram evolved

that depicted all the pieces represented during the data analysis. The resultant diagram illustrated a parsimonious process within the context of the core theme of *transformed fathering* (Appendix A).

## Trustworthiness of the Theory

In grounded theory, several methods are used to evaluate qualitative procedures and to demonstrate the trustworthiness of the data and its interpretation. Trustworthiness has four components: credibility, transferability, dependability, and confirmability. Thus, the trustworthiness of a theory is established by balancing scientific rigor with the careful preservation of the integrity and meaning of the data provided by the participants (Sandelowski, 1993).

### *Credibility*

Credibility in qualitative research is comparable to the term internal validity in quantitative research. Member checking is a modality used to establish credibility. This process involves a constant checking of the data between the researcher and the participant who supplied the data. I conducted member checks during and immediately after interviews through paraphrasing fathers' statements to summarize main points expressed during the interviews. This allowed the fathers to confirm, correct, clarify, and add additional information to the data. Moreover, member checking became a vehicle for me to validate that the data provided by the participant was what they meant to convey (Lincoln & Guba, 1985). Several of the fathers would use concepts such as *time*, *being there* or phrases like "I just don't know." In these instances, I would ask and encourage

fathers to elaborate further on these terms or clarify their thoughts. At times, what I heard was not what they meant to convey. As I neared the end of the interview, using my interview notes as a resource, I summarized what fathers had said. Often this led to a longer interview because fathers would further clarify information. The following is an example of member checking during an initial interview with a father:

R: Um huh.

F: …I need to find an organization that will show me things, how to help him develop, you know. And, after I get older and my son becomes independent of me, then I'll say I accomplished a lot. I'll say that I have accomplished a lot like taught him what I needed to teach him. Then I could say, you know, then I could tell somebody how to do it the way I did it, you know.

R: So independence for you, the term independence, Ignacio becoming independent is more than a financial, more than just his finances.

F: Right. He's independent from me,

R: What does that mean?

F: That means I'm not giving him, he's not getting everything free, he's earning his own stuff because he's looking out for himself and looking out for his future family.

I believed that with more than half of these fathers, these interviews were the first time that they expressed themselves in this fashion. The effect that their child's chronic

health condition had on them was dramatic. In several instances, the mothers were aware and supportive of their child's father participating in the study. For example, five of the ten mothers were in the same room as the interview was taking place. Others were in the house in another room. I do not believe this dissuaded the fathers from being forthright and honestly assessing their emotional, cognitive, and physical reactions and responses to their child's chronic health condition. In fact, often times the mothers would validate the father's expressions. When fathers become too emotional to continue the interview, mothers who were in close proximity would encourage them to continue by placing an arm around them.

I also asked two colleagues familiar with qualitative research to participate in peer debriefings. While these colleagues work in an environment that is primarily Mexican-American, their research endeavors do not focus on Mexican-American men or children with chronic health conditions. In informal and periodic meetings, I was able to test ideas and thoughts about my themes and supporting categories. These debriefings helped me to be more reflective about the process. After each interview with the fathers and peer debriefings, I kept a journal that served as a vehicle to clear my mind of emotions and feelings that might have influenced my judgment or clouded my analysis of the data. Lincoln and Guba (1985) suggest peer debriefing as a most useful technique for establishing credibility.

*Transferability*

Transferability in qualitative research parallels external validity in quantitative research (Lincoln & Guba, 1985). The intent of the study is to generate theory or integrate sets of hypotheses that might be useful to other researchers. These researchers might recognize similar phenomena with and among other populations (Glaser, 1978; Lincoln & Guba, 1985). Although this study will be useful in producing "either the same or very similar theoretical explanations about the phenomenon" of fatherhood (Strauss & Corbin, 1998, p. 267), fathers in this study were deliberately selected to represent a certain segment of the total population. With this in mind, the theoretical outcome of this project provides insights of Mexican-American fathers who have a child with a chronic health condition.

*Dependability* and *Confirmability*

*Dependability* and *confirmability* of the data are woven throughout the analysis process. These two components of trustworthiness are important in maintaining the integrity of the research. Dependability is concerned with the consistency, stability, and accuracy of an instrument over time. A fundamental issue is whether any changes in that instrument have a coherent and readable trail (Marks & Dollahite, 2001). The interviews were not constrained to the questions in the interview guide; rather, the interview guide provided a framework in which other questions naturally happened during the interview process. Thus some of the interview questions were revised when questions appeared to ask for the same information or the question was not clear to the father.

*Confirmability* is also essential to the trustworthiness of the study, in that it helped me to become aware of my own biases in interpreting and reporting results. Confirmability has its counterpart in quantitative methods, where it refers to the demand on researchers to exercise objectivity (Marks & Dollahite, 2001). I maintained a reflective journal to help me to recognize potential influences that may have led me to overlook salient features or concepts, skew the collection and reporting of data, or distort interpretations of results. For example, I carefully analyzed possible influences derived from my professional experiences with Mexican-American families. I practice in a clinical setting, where I work with predominantly Mexican-American families who have children with chronic health conditions. I worked with agencies that may have as their clients, families that I personally have been involved in their child's direct care. For those reasons, I was alert to the effects those contacts might have had on my ability to evaluate and interpret data accurately. Although a majority of the children had been seen at the children's hospital where I was employed, I did not interview any fathers for this study with whom I had previously taken care of their child in the clinical setting.

## Self as Instrument

### *Preparation*

I have had several opportunities during my doctoral program to engage in qualitative research. Knowing my research interest, each paper written, articles searched, selected, read, and reviewed focused on Mexican-Americans, fatherhood, and children with chronic health conditions. One of my courses focused on qualitative research

methodology for the entire semester. The class introduced me to leading researchers in qualitative research. For a class exercise, I interviewed two Mexican-American fathers who had a child with a chronic health condition. I thought of the exercise as a preparation for my dissertation and essentially used it a as pilot for my area of research interest. This exercise taught me several things: always have back-up tapes and do not conduct interviews outside. Moreover the exercise taught me how to develop interview questions, how to ask questions and not sound robotic, how to develop my interview techniques, and recognize the importance of active listening. I was also a research assistant during one summer. The researcher I was assisting wanted qualitative data analyzed. I listened to interviews via audiotape, made notations, and extracted information that was vital to the qualitative component of her research. These situations exposed me to the rudiments of qualitative research methods, qualitative researchers, and qualitative literature.

*Influences*

I was cognizant of how my appearance might influence each father's responses to my questions. Initially, I planned to dress very professionally and wear a lab coat to each interview. At first, I thought this would be helpful in establishing professional boundaries. However, after further consideration, I decided that my initial introduction to the fathers via social worker or case manager would provide the defining role of researcher and participant. Consequently, when the fathers and I arranged our first interviews, I dressed casual. I made every effort to appear comfortable. I thought this approach would ease any discomfort of "knowing" the father was being interviewed. I

think this approach in presentation was helpful. In fact, the most intimidating factor of the interview proved to be the tape-recorder.

When I realized after the first interview how intimidating the tape recorder was, I purchased a new smaller tape recorder with a microphone. I then placed the tape recorder on the floor or side table and placed the microphone between the father and myself. However, prior to starting the taped interview and after the consent form was signed, I would begin with small talk, “The weather is really nice today” or “you gave great directions”. For the most part this approach seemed to provide a relaxing atmosphere and within several minutes, the father and I forgot that the tape recorder was there.

Moreover, trying to manage my first years in academic teaching, personal obligations, and writing my dissertation was a tremendously challenging undertaking. While the motivation to continue writing was there, hitting many roadblocks in the recruitment phase, finding a reliable transcriber, and discovering solid blocks of times to complete data analysis were difficult. I had received increased responsibilities for my students and colleagues when I was promoted to chair of the Child Health department in the school of nursing where I teach. I had also discovered that making the transition from the hospital clinician to academe was not easy for me.

However, my job allowed me the opportunity to take one day out of the workweek to complete my dissertation. I used this time fully sending emails, making phone calls, making appointments, driving to agencies in the San Antonio and Austin area distributing flyers, meeting with program directors, data collection, and data

analysis. I do believe that I have grown personally from these fathers' stories. As a novice researcher and professionally I have gained immensely by this experience, it has motivated me to continue in this area of research.

*Summary*

I have attempted to outline in previous sections of this chapter, grounded theory methods implemented for this study. It is quite possible that what emerges from the interviews using grounded theory methodology will not occur in the same way. This is because in grounded theory, the analytic process is solely dependant upon the interaction between the data and the creative process of the researcher (Glaser, 1978). As Denzin (1998) describes, "the qualitative researcher faces the difficult task of making sense of what has been learned" (p. 313). However, how one interprets codes, memos, supporting categories, themes, and the core theme is made available as evidence of theory development.

## CHAPTER FOUR

## THEORY: AN OVERVIEW

Some start out with a big story
that shrinks

Some stories accumulate over power
like a sky gathering clouds,
quietly, quietly,
till the story rains around you.

Some get tired of the same old story
and quit speaking;
a farmer leaning into
his row of potatoes,
a mother walking the same child
to school.
What will we learn today?
There should be an answer and
it should change.

Naomi Shihab Nye, *Yellow Glove*
(used with permission)

This chapter presents the stories of 10 Mexican-American fathers describing their entrée into the world of being a father of a child with a chronic health condition. The purpose of this study was to identify factors that influenced fatherhood among Mexican-American fathers with one or more children with a chronic health condition. For these Mexican-American men, fatherhood meant not being absent, unconcerned, or solely a breadwinner and disciplinarian. Instead, they changed previous behaviors to convey more than a passive presence in their child's life. Consequently, illustrated in this chapter is the process of *transformed fathering*.

*Transformed fathering* becomes a journey for 10 men that is a profound personal internal exploration of personhood. This journey interpolates previous fathering behaviors by redefining a personal identity of fatherhood as a deep commitment to their child. This commitment extends beyond the biological process of fathering a child. Fatherhood is an active presence that cultivates a dyadic relationship; engaging fathers in their child's life. In order for this *process* to occur, fathers faced the challenges of *adjusting* to their child and the diagnosis of a chronic health condition. In turn, *taking care of business* became an important call to action for them to understand and make meaning out of their child's health condition. Furthermore, a personal transformation occurred generated by their child's chronic health condition that required an introspection of personal philosophies, feelings, desires, and responsibilities.

According to Gutmann (1996) male identities, particularly fatherhood for Mexican-American men encompasses cultural, historical, political, and structural influences. Furthermore, male identity is defined by what men say and do **to be** men rather than what men say and do. As they sifted through the event of their child's chronic health condition, 10 fathers consciously decided to change their behaviors to become more active in their child's life. *Adjusting* occurred with the *birth of their child* or shortly thereafter at the time of diagnosis, the confrontation of *Emotionally overwhelming, overloading of medical information, uncertainty*..

*Taking care of business* involved *absorbing the information*, and *being there* for their child and family. Thereby contributing to their child's development through

activities such as changing diapers, playing with the child, setting limits, making their child laugh, giving medications and feedings by means of a gastrostomy tube, attending doctor's appointments, participating in therapies, and providing financial support. Furthermore, *deepening relationships* with the mother of their child and their older children was a key component in *taking care of business* and an *increasing of their faith*.. Pseudonyms are used in the fathers' stories.

## Adjusting

Confronted with a chronic health condition can be devastating for a family. When a chronic health condition affects children, some of the most vulnerable members of the population, questions often go unanswered. A family faced with unexpected dilemmas can change their lives forever. For these 10 men, faced with hearing, "your child has {condition}," abruptly forced them into an unexpected situation. Suddenly, the expectation of a typically developed child was not their reality. The theme depicts how each father is *adjusting* to the unexpected challenges (*birth of their child, Emotionally overwhelming, becoming familiar with an unfamiliar phenomenon, and uncertainty)* associated with their child's chronic health condition and subsequent outcomes dictating the external behaviors that defined fatherhood for them.

### *Birth of Their Child*

*Adjusting* for these fathers began with the *birth of their child.* For some of these fathers their child's birth was a typical, ordinary event. Soon after the birth, their dreams altered. For some fathers, they noticed differences in this child as they made comparisons

to their older children when they were the age of their sibling. Yet for others it was the realization that when their child reached a certain age, they as fathers would have to adjust to their child's abilities.

Mr. Ramiriz's period of *adjusting* to his son's diagnosis of severe Cerebral Palsy began at the time of birth and reached a pivotal point when his son reached the age of 3-years:

> For me to celebrate, he's {Ignacio's} my first son, my first child. {Is to pass a box of cigars} around to the other guys so we could smoke cigars. I don't smoke, but that would be the day I would be smoking a cigar, just so I could say that's a celebration. A lot of fathers do that, they buy cigars and they're happy they have their son…. It's an accomplishment, that he's gotten bigger and he has made it through a lot of adversity, I would say. A lot of complications he has gone through and, ah, we were expecting the perfect child, but, you know, due to the circumstances, he's not… and we're willing to do the best we can to get him to that perfection stage, you know.

Mr. Zertuche, a father of a 5-year-old with Cerebral Palsy, describes how the birth of his son and the subsequent diagnosis became an event of *adjusting* for him:

> That (Cerebral Palsy) was diagnosed, from what I understand, about 6 or 8 months into-after his birth. He was premature I believe about 30 days. And we didn't notice it until a couple of things happened and we're not exactly sure…a couple of weeks, early on, {when} he arrived here at home he showed some signs

of discolor, yellow, orange, or orange…high bilirubin they called it jaundice. We felt it came from, because he was too early, because of labor it could have been, if not, we don't know....We've settled to the point where, you know, he's a gift from our creator and we've since then, {we've} just done some adjustments, or a lot of adjustment you could say with that…there's special needs that we need to adjust to because we can't take for granted that at the age of five, now, that he can up and walk and do some of the things like feed himself.

Mr Zertuche is describing a period of adjustment, when he and his family had to accept his son Able's physical limitations. At 5 years of age, it was unlikely that Able would gain some of the developmental skills that a typically developed 5 year old child would exhibit. For Mr. Zertuche, Able reaching 5 years was a marker of what to expect in terms of abilities expectations and limitations in his son's future.

Mr. Solis describes his son's chronic health condition, inconsistent information from the healthcare community, and his son's most recent accomplishments. Mr. Solis is *adjusting* to what his son does and cannot do in relation to gross motor and cognitive skills. These accomplishments are pivotal for Mr. Solis. His son is gaining "new life skills." It is Mr. Solis' hope that his son will develop skills to function in society.

Mr Solis: … research we've just done, reading articles and stuff, he does have signs of Autism and he might have a little…well, we went to another neuro-psychologist, um, through the school 'cause we wanted to have an outside evaluator. So, they set us up with this doctor, and she just got done with

evaluating him. I actually went yesterday and had the follow-up with her…he has Autism Special Disorder. It's, it's, it's not like, it's just a wide range of Autisms. He'll (Henry) be in life skills next year. Yeah, that's our whole goal and just, he's getting better. He's actually doing a lot better feeding himself, actually drinking out of a regular cup by himself, so that's, that's exciting. He doesn't really have to use a sippy cup anymore, and we're working on the potty training.

A father of a 15-month-old daughter, who suffered a stroke at four months of age, acknowledged his child's limitations but also spoke of his aspirations for her:

Mr. Quiere: Um, I mean she (Jackie) is disabled, but she's just, you know, she's just right there, just that much further, and she'll be caught up to her age, you know, and I mean, it's just, I guess that's, you know, just trying to help her get to where, you know. She can do stuff and she can run around with her sisters, you know, she can play with her sisters and laugh with them, you know. She can go walk into their room and wake them up when they're asleep or something, you know.

These descriptions of *adjusting* to their child's chronic health condition that began at the *birth of their child,* was a unique experience for these fathers. Recognizing the nature and consequence of the chronic health condition, focused these fathers attention on their child's abilities not their child's inabilities. This process of recognition was not an easy endeavor. Several of the fathers described periods of agonizing comprehension that

did not come to fruition until their child reached a developmental stage where developmental milestones were not being met.

*Emotionally Overwhelming*

Hearing that their child had a chronic health condition and seeing their child's inability to accomplish certain tasks was *emotionally overwhelming* for these fathers. Additionally, most fathers admitted that their concerns centered on their child gaining financial independence and care as they moved toward adulthood. "Will I be able to stay around and I still have the finances available? Who will take care of him?" However, the anticipation of their child not having the abilities to run, play and participate in other activities on par with typically developed children, in conjunction with their child's chronic health condition, became an overwhelming concern.

For Mr. Williams, whose son was diagnosed with Down's syndrome, the degree of his emotional burden came to the surface during a solo hunting trip. He stated:

> …I guess, I took it hard (hearing the diagnosis). I know I did. And it was right in October and then, ah, I do a little bit of hunting and stuff like that. So I'd find myself kind of real down and out about it. I'd be at the ranch somewhere, in the middle of nowhere, by myself… And I'd sit there and cry about it, you know.

Mr. Quire's daughter had bacterial meningitis and suffered a right-sided stroke during transportation to the pediatric intensive care unit at four months of age. She was 18-months old at the time of the interview. He tearfully describes the events that led up to her hospitalization and subsequent outcome:

Yeah, ah Erica (mother of the child) hadn't gotten there yet, the nurse kind of started to ask me some questions, ah, to see what I knew about what was going on and then she was kind of explaining some things. I know when Erica got there, you know, I just kind of let go and everything you know just, just, I cried for a day you know….

Mr. Trevino's son Greg was diagnosed with Autism at 18 months of age. He describes his son's diagnosis and subsequent limitations. The emotional effect on him and the type of relationship he would have with his son was becoming a reality he had not expected.

Mr. Trevino: I think one of the biggest things that kind of hit me-when it all came about-was realizing that that {Autism} may be a lot different than what I imagined it would be. You know, so, I guess, the son that maybe I dreamed about was going to be a little different, and we have to work a little bit harder, I guess, to build that kind of a relationship. 'Cause at this point, yeah, if I wanted to take him (Greg) outside, it will take him a little bit longer to teach him, you know, to kick a ball, how to hit a ball, or something like that. But, yeah, just realizing that it's going to be a little bit different path than I imagined you know…

Upon hearing that his first-born child Eliana was diagnosed with Downs Syndrome, Mr. Van describes his initial emotional response.

Mr. Van: When we were at the hospital, one thing that I did see is that other side. You know, when we were there, because *mija* was there for a month afterwards,

> ah, to help her with her feeding and just to monitor. I could see the parents' faces when they're happy to take their children home with them the hard part for me was not being able to. Ah, how could I be happy for them when I'm going through my own little, you know. It was first, first thing was it was a shock that we didn't know (prenatally). The other thing is I didn't know what that was. Yeah, I've heard about it but I've never paid attention to it cause no one in my family had it (Downs Syndrome).

The emotional responses elicited by the *birth of their child* and their child's diagnosis were foreign to these fathers. Several of them admitted that prior to their child's birth, they had not openly expressed themselves to their wives in such an emotional way. Their emotional responses were a part of their *adjusting* to their child's diagnosis and became a pivotal part of *transformed fathering.*

*Becoming familiar with an unfamiliar phenomenon*

Along with the *overwhelming emotional burden* of *adjusting* to their child's diagnosis, there was an *overloading of medical information*. These father described situations where they were faced with navigating the healthcare system, and interpreting unclear medical language and terminology used by healthcare personnel. With this, there was a sense of isolation felt by some fathers of being excluded from their child's care.

Mr. Trevino describes how because of his son's diagnosis he and his wife sought information from various resources. This activity was vital part of becoming familiar with an unfamiliar phenomenon.

> Mr. Trevino: It's like we wanted to learn as much as we can about {Autism} from as many people which is why we've enlisted so much support I think, over the past couple of years with this. …We're getting other peoples' perspectives and definitely getting to know a lot, done a lot of workshops and conferences and things like that. …Yeah, a lot of it is just kind of getting to know more about, you know, the diagnosis itself and then, of course, seeing how that relates to Greg and then being able to apply it also.

Other fathers found that the medical information presented led to inconsistencies in what healthcare personnel told them and what they experienced. This proved to be challenging and frustrating. Mr. Xander, who has a 2-year-old daughter with a rare neurologic disorder, puts it this way:

> And, ah, her (Clare) doctor, ah, well, he was telling us that everything was fine. So, it was like if she's fine why isn't she trying to walk, or, or even, you know, baby talk and stuff like that. There was a lot of little stuff that was unusual…and we find out that her ankles were still…they weren't developing…they would tell us that her legs were weak. {That} was hard because like when you would have her in bed she would push. I mean you felt the strength of her on your legs and it was like, "I don't understand it". They keep saying that she's weak, but at the same time you feel her try to stand her…she would stand up.

While all of the fathers commented on inconsistent and "hard to understand" communications they had with healthcare professionals, a few fathers also became aware

of the lack of inclusion they received from healthcare personnel. For example, Mr. Quiere is a stay-at-home father. He is the primary caregiver for his daughter. While Jackie was in the hospital he stayed at her bedside, Jackie's mother worked outside the home and visited after work. Yet, despite his daily presence, healthcare professionals would give him limited or no information. He not only felt *becoming familiar with an unfamiliar phenomenon* but felt that he was treated differently and was given limited information because he was a man and not the child's mother.

> Mr. Quiere**:** You know, we're people too…and I was like hey I'm here. I've been here all day, remember. You could have told me that earlier, you know…{It made me feel} ah, just kind of like, "Oh, he's just Dad, you know. He probably won't tell Mom the message the right way or something. He won't give her everything. Maybe we should write it down for him or something". And it's like, "No I listen, I do I really listen"…Yeah, you know, I was, I want to know what's going on. You know, that's why I'm here so, I mean yeah, I guess yeah, you know, now that I think about it, it did kind of make me feel like wow what am I doing here, you know.

The above scenario is not uncommon. Household dynamics and social constructs have changed dramatically over the past 20 years. Although some may consider men the primary wage earners, women are also workers and have increased their wage-earning capacity. Consequently, for some households, women earn more than men do and it becomes beneficial for the father to stay at home. Because of this choice, families spend

less on day care, the child stays in a familiar environment, the father-child relationship is strengthened, and appointments to physician's offices and therapies are easier to manage. This was the case in the Quiere household.

*Uncertainty*

Some fathers were concerned about their child's future. As their child moved closer to adulthood, their concerns centered around their child's ability to integrate into a society that is often intolerant of persons who are different and dependent. While discussing his hopes for his child's future potential, one father acknowledged the expectancy of his son's birth, the reality of the birth, and his underlying anxiety about the child's future after the father's eventual death:

> Mr. Ramiriz: For many years I've been looking forward to being a father and just three years ago I got my first chance to be a father, you know. A lot of people my age have been fathers since they were 15 and most of their kids are fully grown, graduating or going off to college and I'm, you know, at my age and my time, and I barely have my first 2-year old, you know, and I'm 39 right now…. I won't see him as a football player or a basketball player; it's too much physical activity for him. I just hope he learns how to play chess…. You know what I mean. I want him to learn how to, you know, tell the difference between right and wrong and how to look out for himself, keep them vultures away from him, you know…and, after I get older and my son becomes independent of me, and after I'm gone, then I'll say I accomplished a lot. I'll, I'll, I'll say that I have accomplished a lot like

taught him what I needed to teach him. Then I could say, you know, and then I could tell somebody how to do it the way I did it, you know?

Mr. Zertuche is a father of a 5-year-old child with severe Cerebral Palsy. His son is wheel-chair bound and requires "constant 24-hour care." He further describes his son's care as "the day-to-day grinding needs…there's more energy involved participating on a regular basis." Here Mr. Zertuche explains the challenges, as well as his concerns for Adam's future healthcare needs and outcomes:

> I think one of the challenges if nothing else is the physical well-being, because we don't know enough of the things {that's what rest in my mind} later on in the future because as he gains his weight, you know, and as we get older, you know, what are the areas that we need to look {into} so if anything, if any concern, it would be that, kind of tucks in the back of my mind

In his interview, Mr. Williams compared the independence of his oldest child with the dependence of his 2-year old son, who has Down's syndrome. He stated:

> Um, Um, I kind of just see a buddy for the rest of my life, in a way we didn't know if, he, you know, everything was going to be okay, or if he'd live, you know, or not live, or what the situation might be. At first, when we did find out it was a boy, the only thing I kind of didn't know, just him being born and all, having another boy around, its how I was going to be equal to both of them. It was kind of like how am I going to put attention to both of them and be the same with both. But then once he was born this way, it kind of changed things a little

bit…I knew I was going to have to pay more attention to him but yet…the attention was going to be just a little different. Chance, right now, he's more with the therapy and, and doctor's visits and just different things and I guess later on down the road, it might be about the same way. I think they're, they're gonna be different in their own way so I'm going to treat them different…but it's, I don't know, it, it's a little hard sometimes, just, just, the not knowing if he'll catch on or if he will or won't….

Mr. Trevino has a son who was diagnosed with Autism at the age of 18-months. Now that Greg is 4-years-old, his father's primary concern is his son's current level of language acquisition and how it will effect his socialization as he gets older:

…some of the biggest concerns will have to be his socialization, and, his, ah, his language, I think his language is probably going to take time in terms of what we're really worried about or wanting him to establish. The socialization, I think, can probably occur a little bit better as he gets older, we'll be able to reason with him a little bit more. But, ah, but the language, I think, is our biggest focus right now and, you know, concerns us that we're at a point where he's going to get to a certain age and at that age he's gonna, it's gonna kind of determine that he's either going to be verbal or he's not going to be verbal and, you know, everyday we kind of get closer to that so we're constantly working towards it. {I hope} he'll be able to overcome the language barrier that he's kind of established but then also, um, just being able to adapt in his environment, I think that, yeah,

adaptation, that's going to be kind of difficult and I think, I hope that he's able to do that very well.

*Adjusting* as described above was a new task for these fathers. None of these fathers had prior first hand experience with having a child with a chronic health condition. Although , a few of the fathers had friends who a child or a relative diagnosed with a chronic health condition, that experience had been tangential and did not prepare them for their own child. Yet, their experience with healthcare, confronting deep emotions, the uncertain outcomes, and responsibilities for the child, were determinants of what course of actions these fathers chose in caring for their child.

## Taking Care of Business

For these 10 fathers, the initial step of *taking care of business,* in relation to their child's chronic health condition, was defining, understanding, and interpreting their child's chronic health condition through *absorbing information*. The crux of these fathers' *taking care of business* was found in them making sense of the medical information given by healthcare professionals. With this in mind, for them, it became an instinctive and necessary process on which to focus: the child's well-being. *Being there* was very important to these fathers. Based on the experiences with their own fathers, they consciously made efforts to demonstrate different or similar actions of their own father with their child. Therefore many of them redefined *being there* based on their own parental influences. Moreover, *being there* was not limited to their child with the chronic health condition. *Being there* included a more active presence in the lives of their older

children and the connection they had with their wives, thereby enhancing the *family and marital relationships.* I decided to place *increasing faith* under this theme. It would appear that these fathers had some belief in a higher power and attended church on an irregular basis prior to their child being born, however part of the action of *taking care of business* included prayer and church support groups.

I began each interview with a broad question of "tell me about your child" and each father would tell me his child's name and define the child's health condition. It was as if they saw their child and his or her condition as one. The salient concerns of these fathers continued as they tried to comprehend all that their child's chronic health condition entailed. The openness and enthusiasm to share what they had found out about their child's chronic health condition was demonstrated during the interviews.

*Absorbing Information*

For these fathers *absorbing information* meant making sense out of their child's chronic health condition. After sorting through what healthcare personnel told them, and through their own research about their child's diagnosis, fathers translated the medical information into words that had meaning for them. By doing so, each father was able to articulate the nature of his child's health condition and share with others. Below are three fathers' descriptions of their child's health condition, as they understood it.

> Mr. Ramiriz: You know, we don't know what's going on, we don't know what's happening. You could say that the blood flow from the ventricle four to ventricle two, what you are talking about. I don't understand. Like my experience with

{a}gasket. They're going to put a shunt in him to drain the fluid. To me that sounds like they put a little valve in the pipe like in the automobile. You or you're seeing your AC leak in the inside of your vehicle what do you need. Oh, I need a drain tube to make that condensation go out, outside the car. It's coming inside the car; I need to make it go outside, and so you put a hose and a clamp and then it drains outside. Because you can't help it, the water is going to be developing because of the atmosphere you know. If you have a hot place here and a cold place here and then there's something in between then there's gonna be condensation, you know, cause of the oxygen and oil. See that I understand. But if you try to put mechanical into health, its two different things you know. They need to tell us on our level. Not you know, the doctor says hydrocephalus. When he said the first word hydrocephalus to me it's like, I understand syphilis, but I don't. How in the world did you come up with hydro you know? But then when you start reading, explained to you. Oh, okay, so…So then I go tell my guys my friends at work, hydrocephalus, I'm pretty sure they understood the word syphilis. And they're like, you know, freaking out, well what does that mean. Water in the brain, Oh, I thought it was something else.

Mr. Zertuche: It's called Cerebral Palsy, which is from what I understand, and I'm no physician or just how I understand from a layman's term, ah, his nerves within the body are uncontrollable, so there's a lot of shaking. He does take medication

for that to reduce it because there's a lot of stiffness in his body. So, again, especially on his left side when he moves his arm, but overall there's no control. Not that out of control, but no control to grab or step or things like that.

Mr. Trevino: Autism, well, ah, that it basically encompasses, ah, three different areas. One, of course, you know being, ah, verbal language, ah, which you know he doesn't have. Ah, the second aspect of it would be social interactions and that is very tough for him because he, you know, doesn't do well with people he doesn't know or environments that are, you know, very crowded. He doesn't really enjoy those very much at all. He takes a little while to warm up to people, you have to kind of be around him, he has to recognize you I guess, not to see people as a threat or something, so until he feels more comfortable. And then, the other, of course is behavioral. He has some sensory integration issues that he has to do things constantly in order to, you know, meet some of his sensory needs. He needs a lot of deep pressure, so a lot of things he'll do is, he'll, ah, run around a lot. He likes to, ah, you know do things like swings and he does have some type of aversions to certain types of food, mainly because of textures.

*Absorbing information* about their child's chronic health condition yielded answers that assisted the fathers to understand how much their child would need them in their life. Defining the condition in terms they could understand was imperative for these

fathers. Through this understanding, a realization of their role in their child's life became apparent.

*Being There*

Through my interviews, it became apparent that these fathers had not previously been given a venue to express their thoughts about their child who had a chronic health condition. They had not been given the opportunity to convey how their child's chronic health condition affected them as men and as fathers. *Being there* for their child was more than a passive presence. Their active participation in their child's life improved their ability to see and appreciate incremental developmental changes in their child, to recognize and interpret their child's non-verbal expressions as visual cues of their needs, and to foster an attachment with their child. Moreover, *being there* not only included the amount of time they spent with their child, but the quality of that time. For example, time meant more than showing up at games, but it meant physical contact from fathers as evidenced through play, hugs and conversations**.** Mr. Xander the father of a 2-year-old with an unknown neuromuscular disorder, stated:

> Ah, she's (Clare) been, ah, we noticed that like at 9 or 10 {months}she wouldn't like try to crawl or, or, or, try to get up by herself, and, ah, we started really paying attention to it when she was like 11 months old because all my other kids were walking by then and grabbing stuff and everything. And it was just, ah, she was also, ah, not only that, but she ah, she had a lot of problems with congestion. So we, she spent, ah, like a week or two in the hospital, getting treatments. Ah,

there was a lot of little stuff that we were noticing different. Compared to my other three kids that, that ah, it just, what's going on, and, of course, we started, ah, looking and getting tests. And, and, of course, when you've this, my other three kids, you try to compare and try to remember, Irene, and Roland Joshua did this…or Jesse, and, of course, it's like come on baby start walking or something.

Mr. Ureste, who has a 3-year-old daughter diagnosed with Sprangles syndrome, explains:

{Dionne} just wasn't reaching her developmental milestones. She was still flat on her back, she wasn't able to roll over, but it was at 6-months. When it came time for her to walk or when she was supposed to walk, she wasn't able too. She couldn't bend her knees at that age. She could turn her head this way or that way. We just noticed that she wasn't doing things like {our} son did at that age.

Mr. Zertuche explains his role in his son's life:

I think the key in providing the best form of care is stimulation, the mind, and he has a great one. {Able} knows, knows his surroundings; he speaks with his eyes. Ah, and of course, you know, among the, ah, the special expressions when he's sad and happy. You see maybe uncomfortable and the tension between his sister and him, or he's sad because they changed the channel. He'll cry or he'll holler, get uneasy, and he'll groan if he's wet and things like that. So back to answering your question: yes, feeding, changing the diapers, medication. But here's one of the things I feel is my responsibility when I'm home, ah, is playing, spending time, and you can tell he loves to read, to be read {to} because there is something

different about his expression when he hears you read. His eyes get big, and he smiles and he groans as if he's laughing, and then we wrestle. Now you say how do you wrestle Cerebral Palsy. Well, it's not physical contact, and we need to do some of things all boys, you can tell, different from a girl, when they're into this wrestling with their father. There's a certain groaning and, and, and their mouth opens and there's this little giggle and, and so I roll him over from side to side and I, I, I rub my chin on his side, or I'll blow, I'll, I'll kind of make these noises under his arm or his neck. So, he likes that. I get one of his dolls, and I'll pretend I'm a puppet. And I'll hide myself and I'll bring the puppet out and it's like I'm talking to him. So again, when I hear him, that certain noise he makes, I know he's enjoying it. And if he's not then maybe he's maybe distracted by the TV or whatever, but for the most part, if we interact, his complete attention [is] to you. So wrestle, reading, ah, oh gosh, swinging. We swam yesterday and when we swam he has a, has a blown-up kind of like a what would you call, that it's kind of like a lifeguard thing.

While Mr. Zertuche identifies many elements of care giving, his primary responsibility is stimulation. He does this with somewhat aggressive interactions such as wrestling to less aggressive ones such as swimming. The physical activity for the child is as important to Mr. Zertuche as reading and role-playing with Able's dolls: stimulation equals interaction, which Mr. Zertuche sees as his responsibility. For Mr. Zertuche, this role stimulates his son's mind and helps keep his attention. This example shows how Mr.

Zertuche's considers his role in his son's life as one of engagement. Active participation with his son in as many activities as possible provides a reciprocal development for father and son: between father and son.

Mr. Solis has a five –year-old son diagnosed with Autism Spatial Disorder. He expresses what *being there* means to him in this way:

> …being there, going to meet all his doctors, knowing his therapists, just learning what they're doing so you can come do it at home with him and help him out when it's just you and him, not just, not just be a Dad that's just there, and just watching the kid and not knowing what's going on. Try to be involved, just get involved in his life.

The codes for the theme of *being there* were very common threads apparent in the interviews with the ten fathers. The analysis revealed a message of actively participating in their child's life in some aspect. Whether it was through play, participating in sports activities, attending conferences related to their child's chronic health condition, taking their child to different therapies, or disciplining their children. For these fathers, engaging in activities that are multi-faceted and varied cultivated and developed a sense of being part of their child's life that may have been overlooked with his other children. Mr. Xander puts it this way:

> It's just hard to see it, but, but it's taught me to appreciate her even more then. I was gone a lot of times with my other three kids and now, this, this little girl's got me now. And, of course, she's my last one, and, it's just, I've gone out of my way

to be there for her and probably because I didn't spend as much time with my other three kids.

*Being there* for their child with a chronic health condition was significant for these fathers in recognizing their child has needs and providing positive support for their child's developmental outcomes. Conversely, the children changed these fathers' lives forever.

*Family/Martial Relationships*

Mexican-American men are commonly viewed as hard-drinking, philandering men, strong disciplinarians that are distant from family interactions, providing the primary finances in the household (Brandis, 2002; Gutmann, 1997). In contrast, for these 10 men, being the father of a child with a chronic health condition was not about dominance, marginalization, and subordination in the household. Instead, fatherhood for these men was about a mutual respect and a partnership between mother, father, and their children.

For these fathers, family cohesiveness was paramount for a successful outcome for their child with a chronic health condition within the context of the family and society. All the fathers described similar views on what this cohesiveness entailed. All immediate family members held some responsibility in seeing to the well-being of their sibling. This included sharing of care duties; medication administration, participation in physical therapies, and taking the child to doctor's appointments. However, the family's

cohesiveness began with the relationship between the mother and the father. Mr. Van tearfully explains it this way:

> …it's a team effort, me and my wife. We, ah, try to give each other that, that space, sometimes. Cause, you know, having a child, it takes a lot out of you, and what we do is we pretty much have a plan where I help out as much as I can, but because I have to work, you know, and pretty much I am the breadwinner, um, she takes a lot more responsibility as far as making sure that she takes care of {Clare} throughout the days. Ah, but when I come home then I take over. So, we kind of shift. It's like a shift change…ah, it's made me understand to open up to my wife more. So our relationship is also different. Whereas, before I would handle that {by myself}..I was more, ah, you know kept everything inside. But because this was overwhelming, or you know it was like different…. Nothing I've ever you know experienced ah, you know me and my wife,…So I and my wife have also changed.

Mr. Quiere and Mr. Ramiriz both put it plainly:

> Mr. Quiere: Oh yeah…without a "we" I mean it would be nothing, it really would. And I mean I think she could handle it by herself but you know, I just you know she's that much stronger, but I think {Jackie} makes me stronger. She, you know, gives me that strength to be, you know, to, I mean, yeah, but just…I sometimes I mess it up, 'did you give her her medicine you know'. But you know

we do it back and forth to each other. So its like we know that it's never gonna be an issue to where one of us is gonna forget.

Mr. Ramiriz: It has to be a we…It has to be the wife and me. I cannot exclude…just because we're separated it doesn't mean that I have to separate her from our lives, and making Robbie grow…So it has to be a we.

All of these fathers expressed recognition of a partnership with the mother that is required for their child to succeed in an environment that will maximize their child's potential. In some of the interviews, it appeared that the fathers were falling in love again with the mother; acknowledging their wives' self-sacrifice with their older children. For these fathers, the negative aspect of machismo was not an option, particularly as it related to their family and their child with a chronic health condition.

Mr. Zertuche: Gripping the sum of the realization, yes. I think some of the things that, the problem that I was having was because I was selfish and I'll admit it you know sometimes I can come up with conclusions, you know. I sometimes do an evaluation and when you ask me that question, that's the only answer I think I can really be almost confident and sure of. That, that was just being selfish and I was thinking of David, the father, or not, you know, others. I think, I don't know whether if its in Hispanic men in particular, but we carry a pride thing…so whatever happens, ah, in the field of, ah, ah, of our norm, ah, and if it comes out of sync, we wonder why, we try to fix immediately and some things we can't fix ,

> ah, we become uncomfortable, and if it's too long of a fix or an unfixed situation. I'm speaking for myself, I carried some type of chip on my shoulders and I've kind of carried that with me because I've always want an edge and I've always wanted that, the extra step…you know what, I think even more, it's given me a different perspective than that because I've realized this is my situation now what's the best for him that I can provide: my service as a father to him and that's an angle that I'm faced with, to do the best I can to provide the best need for my son, Able, I'll do it. And my best right now is attention, interaction, being involved.

Recognizing previous behaviors of being a distant father to their older children, was a recurrent assertion with those fathers who were not first time dads. The *birth of their child*, who had a chronic health condition, altered them in ways that may not have occurred if their child had not been born. "Its something I will never know, but I think she changed me as a man, husband, and into a better father" (Mr. Xander).

*Increasing Faith*

Seven of the 10 fathers expressed their faith and religious experiences as important in thinking about, *adjusting* to, and finally coping with their child's chronic health condition. They felt that their child was a "gift from God," "we are seeking answers through prayer and church family," or "we know that this is God's will." Mr. Trevino's daughter did not meet developmental milestones of a typically developed 6-month-old (e.g. rolling over, picking up objects). Now, at age 3, she still requires

assistance to walk and maintain her balance. After many medical consultations, it was determined that she has a rare congenital anomaly that affects her spine. This diagnosis was unexpected. Mr. Trevino acknowledges that his faith has been an integral part of *adjusting* to his child's illness:

> …Right now, I'm taking it day by day. I think religion has played a large part. If you have a healthy relationship with God, and I'm not saying I'm a saint…but I think that has helped. I have a strong faith with the Lord and that has carried me through, especially through the guilt. My faith is an anchor for me to continue what I'm doing. By no means do I feel pity. God gave me her for a reason.

Mr. Ramiriz expresses his faith and belief in God's will in comparison to other fathers with typically developed children:

> And I thank God every moment of it that we're spending with him. Every day we thank God for everything. And that's the day he was born, it was a very scary feeling…it's just that I had to depend on the Lord Jesus Christ and people praying and medical staff, you know…all I think about {is what} my boy went through worst part than what your boy did. Your…boy is doing a great job because he is a healthy baby, my baby is not healthy, my baby has chronic illnesses, but my baby fought through to survive. He did it for my wife, he did it for me and I could also say that the power of the Lord's Prayer was great because he means a lot to us, he does, and he really does…if it wasn't for faith where would I be at right now. You know, would I be here, would I just say, well, would I be one of these people that

have a sick child and just drop him at an orphanage because he can't walk and talk. Why should I do that, you know? And I believe that God will give us our challenges through life or he wouldn't have given him to me like this.

Seven out of ten fathers interviewed reflected these thought. Although their child had a chronic health condition, their reliance and faith that God had given them this child, sustained them through any challenges they would face.

## Transformed Fathering

Eight out of the 10 fathers had other children before they had a child born with a chronic health condition. Nine of the families were intact couples whose children lived in the same household. The *processes* of *adjustment* and *taking care of business*, led to a personal transformation for these fathers. The collective experiences and behaviors these fathers exhibited prior to their child's birth were often opposite of what their actions are at present. Some of these fathers constantly compared fathering their older children and their involvement now with their child with a chronic health condition.

Mr. Van: I've just been there more. More than usual, than my other kids. I know it's wrong, but, I've always been there for the other kids, but as far as taking extra time, helping my wife do this. It was just, I never really made time. I was there for my kids, football, and stuff like that, soccer. I always still attended their games, but going to [or doing] the extra stuff and helping my wife out, I really didn't get involved…Because, everything was like, they were doing it themselves. And, ah, it was just, now it's, which is, it's good because it's teaching me to really look

into what's going on now, and ah, although I still haven't learned everything that, that, that I should know, I'm just, I'm trying, I'm there, I'm there now. Ah, she needs me, that's the way I see it, that she needs me to be paying a little attention to her.

Mr. Xander's daughter Clare has changed his perspective on fathering, which is not limited to his interactions with her, but made him more aware of his role in his other children's lives. He states:

I, ah, the areas, the thing I just wish {is} that I should have spent more time with my kids when they were small. Ah, not till something happens or something. I just wish I would have been there with my other kids as much as I'm spending time with her…making time. I should have been there more when they needed me, and I'm making more time with my little girl and I want to learn as much as I need to for her…I go back again; I wish I was there when they were that small; it would have been even sweeter. Yes, it would.

Mr. Xander did not shy away from speaking about the type of or level involvement he had with his older children and Clare. He appears to be making up for "lost" moments with his other children through Clare. It is evident that he misses the time when they were little. He has redefined fatherhood as he knew it with his older children and has made a conscious effort to take part in every aspect of Clare's life. Again, his definition of involvement included his older children. He is more attentive to what they are doing now. Another father explained that he had become "more in tune" with his

older children. Wanting to share parts of their life and their "time" with them, he, along with the other fathers, were making every effort to be actively involved in all aspects of their children's life.

Mr. Van was experiencing fatherhood for the first time. His first-born diagnosed with Downs Syndrome. For what the dialogue did not reflect is his emotional expressions throughout this part of the interview. He cried through most of it. This diagnosis and the anticipated long-term needs of his daughter was an emotionally overwhelming experience for him. Yet in the midst of this unpredicted event, he recognized some personal changes had occurred. Changes that he admitted would not have ensued if his daughter had not been born under these circumstances.

> I think it's made me a better person. I think it's made me more caring
>
> Ah, it's made me understand to open up to my wife more. {Therefore}, our relationship is also different. Whereas, before I would handle it {personally} I was more, ah, you know kept everything inside. But because this was overwhelming, or you know it was like different. Nothing I've ever you know experienced… Sometimes we, especially Hispanics we can be all macho, you know. I have learned to put that barrier down: don't be afraid. You know, talk and its okay to cry.

These men were responding to the question of, "How has being father changed you as a person?" These fathers did not hesitate to answer this question. Three of the fathers who participated were first time fathers. The majority had older children and used

their prior fatherhood history as comparison. However, they were quick to point out that this child who had the chronic health condition was the catalyst for redefining their involvement in all their children's lives. Reestablishing or building a connectedness to the child directly effected the developmental relationship of father to child and child to father.

## Conclusion

In this chapter, I presented general findings that emerged from the research, and then described the theory of *transformed fathering*. The major themes and their supporting categories of the theory were *adjusting* and *taking care of business. Adjusting* consists of four supporting categories: *birth of the child, emotionally overwhelming, becoming familiar with an unfamiliar phenomenon, and uncertainty. Taking care of business* consists of *absorbing the information, family and marital relationships, being there, and increasing faith.* The first two phases lead to the consequential phase of *transformed fathering. Transformed fathering* is behaviors and choices, which were precipitated by having a child with a chronic health condition that leads to a motivation to act. These behaviors and choices become salient based on personal identities, cognitive and introspective decision to revolutionize prior behavior. Moreover, *transformed fathering* indirectly contradicts cultural and societal expectations of fatherhood. Thus, *transformed fathering* affects the developmental outcome of the child, the father, and those within his sphere of influence.

# CHAPTER FIVE

# SUMMARY, DISCUSSIONS, IMPLICATIONS

In this chapter, I summarize the research project, and recent literature as it compares to the process of *transformed fathering*. I further offer recommendations for nursing education, clinical practice, suggestions for public policy, and areas of future research.

## Discussion

There is a paucity of research examining Mexican-American families and the effects chronic illness has on the family (Rehm, 1999, 2000, 2003; Rehm & Frank, 2000). Moreover, there has been little research examining minority, or more specifically Mexican-American fathering of children with chronic health conditions. This study was designed to examine what factors influence fatherhood among Mexican-American fathers who have a child with a chronic health condition. Specific questions included the following:

1. How do Mexican-American men define fatherhood?
2. How does having a child with a chronic health condition affect the dyadic relationship between father and child?
3. How does having a child with a chronic health condition affect the father's role in the family and his involvement with the child?

I interviewed 10 fathers who had a child with a chronic health condition living in the San Antonio and Austin communities. I audio-taped interviews, and documented and

maintained detailed field notes. Each interview was transcribed shortly after each interview. Transcripts were analyzed utilizing grounded theory research techniques (Glaser, 1978, Glaser & Strauss, 1967). Transcripts, memos, and field notes were analyzed, through a constant comparison of collected data, until no new information was forthcoming. Several concepts and the interrelationships of these concepts emerged, yielding a more precise integration of a set of hypotheses. A summary of the set of hypotheses is as follows:

Each father met with an unexpected event in the birth of his child who was diagnosed with a chronic health condition. The birth of their child and anticipated long-term effects the health condition would have on their child, affected these fathers deeply. *Adjusting* to their child's health condition significantly affected fathers and catapulted them into action. These fathers decided to make choices that were salient to them that began at the individual level and that would ultimately affect all those in their immediate environments. This active phase was termed *taking care of business*. It was through the phases of *adjusting* to their child's health condition and actively *taking care of business* that these fathers experienced *transformed fathering*.

Historical perspectives and 20th century depictions of fathers, have attempted to clarify varying social constructions of fatherhood. According to Marsiglio, Amato, and Day (2000), these insightful critiques outlining colonial fatherhood to modern fatherhood, have uncovered the variable role of men as fathers. The prevailing convention depicting fathers as a breadwinner, authoritative disciplinarian and aloof, has evolved in part

because of changing social constructs and cultural images of mothering and fathering (Cabrera, Tamis-LeMonda, Bradley, Hofferth, & Lamb, 2000; Griswald, 1993; LaRossa, 1997; McBride, Brown, Bost, Shin, Vaughn, & Korth, 2005; Palkovitz, 2002). Conversely, historic and modern day representations and understandings of fatherhood have been largely drawn from White-middle class sources therefore limiting contemporary representations of fathers from different ethnic, racial, cultural, and economic backgrounds (Townsend, 2002).

Researchers are beginning to examine the relationship fathers have with their child who has a chronic health condition (Peck & Lillibridge, 2003; Ricci & Hoddpp, 2003; Boechler, Harrison, Magill-Evens, 2003). Admittedly, a majority of available research on paternal interactions has generally relied on mothers' reports or perceptions on the impact the child's chronic condition had had on the family, marriage, and fathers (Seideman & Kleine, 1995)

*Literature Re-examined*

The literature presented in Chapter Two offered a general overview of chronic health conditions, fatherhood, and Mexican-American families. I believe at the time of its writing, the literature review captured the essence of the current state of research in these specific areas. However because one of my target audiences are nurses and allied healthcare personnel, I wanted to re-examine the literature in relationship to my study. Therefore, I chose two databases: Cumulative Index for Nursing and Allied Health Literature (CINAHL) and Pub Med and searched articles from the year 2000 to 2005.

These two databases have a worldwide offering of scholarship in healthcare and related fields of study with a bibliography of over 8000.

After using keywords: fathering, fatherhood, and fathers in conjunction with children with chronic health conditions and Mexican-American, no articles were found. What results emanated from the database contained a dearth of first hand accounts by fathers who had a child with a chronic health condition (Chessler & Perry 2001; Peck & Lilibridge, 2006) and fewer studies examined Mexican-American families (Rehm, 2000). When research studies suggested a focus on fathers, *parents* were the focus with few father participants (King, Zwaigenbaum, King, Baxter, Rosenbaum, & Bates, 2006; Ricci & Hodapp, 2003). Since my study participants were fathers of children who had chronic health conditions of Autism, cerebral palsy, and Down's syndrome, I narrowed my search to find articles related to these chronic health conditions and found few articles that were father-centered or had equitable representation of diverse participants (Ricci & Hodapp, 2003; Peck & Lilibridge, 2006)

## Literature and the Theory

### *Adjusting*

Peck and Lillbridge (2006) conducted a qualitative study with four fathers who lived in Australia. Each father lived with their child and during unstructured interviews, described their experience as a father living with a child with a chronic health condition. Similar to my study, these fathers had older children who were typically developed and had one child with a chronic health condition. Because this study was exploratory, the

authors had study participants who had children ranging from two to nine years of age and a variety of chronic health conditions. Although the participants in this study were from a rural community ("isolated from mainstream society" p. 22), the researchers identified four themes that related directly to the experience of loss these fathers encountered living with a child who has a chronic health condition. The themes were loss of pre-conceived expectations of future life, loss of a normal parenting relationship with their child, loss of normal partner relationship and loss of control of time and freedom.

Two of the themes (loss of pre-conceived expectations of future life and loss of a normal parenting relationship with their child) were directly reflective of the supporting categories of *adjusting.* Assumptions and findings mirrored several concepts of *emotionally overwhelming and uncertainty* with my study participants. The other two themes, loss of normal partner relationship and loss of control of time and freedom, were contradictory to the themes *transformed fathering and taking care of business.* In fact, my fathers described stronger relationships with their partners. Peck and Lillibridge's (2003) overall analysis of the data was the loss fathers felt concerning the child's inability to function as a typically developed child. Moreover, the stigmatization fathers felt within the community, having a child with a chronic condition, was paramount in the reported data. These findings support May's (1996) findings that fathers are embarrassed and feel inferior to other fathers who had typically developed children. Consequently, the stigma often associated with a child's chronic health condition was a mediating effect on a father's self-esteem when compared to fathers of typically developed children (Katz &

Kurlix, 2003). Although similar concepts emerged from the data, these last two themes, loss of normal partner relationship and loss of control of time and freedom, that were identified in Peck and Lilibridge's (2003) study, are contradictory to the findings in my overall theory of *transformed fathering.*

In summary, the consistent focus on mothers who have children with chronic conditions is generally an acknowledgement of the mothers who assume primary role in child rearing, their responsiveness to family-oriented scientific inquiries, and their value as knowledgeable informants about their children's lives (Simmerman, Blacher & Baker, 2001; Chesler & Parry, 2001). While positions associated with the supporting themes *birth of the child, emotionally overwhelming, becoming familiar with an unfamiliar phenomenon,* and *uncertainty*, may not appear different from those of the mother's experience, the fact that few studies have attempted to acknowledge fathers' concerns about their child who has a chronic health condition, becomes problematic in child and family research.

*Taking Care of Business*

Matta and Knudson-Martin (2006) conducted a qualitative study that examined how couples co-produce fatherhood within their day-to-day relationships. They also wanted to examine these relationships in a social, cultural, and economic context. The researchers used grounded theory methodology to examine 40 married heterosexual couples: their lived experience with their children who were five years and younger. None of these children had a chronic health condition. However, the results of the study

can help illuminate a deeper understanding of father involvement. The participants from this study represented a diverse population that included Caucasian, African American, Mexican, Asian, and Eastern European men and women.

The data analysis resulted in a social process of responsivity (Matta and Knudson-Martin, 2006). The factors influencing the degree of responsivity were gender constructions, power and the wife's influence, attunement, work schedules, and emotional tradeoffs. Responsivity is defined as the degree to which fathers recognized and attended to the needs of their wives and children. These needs included emotional, household and child-care tasks, and power and fairness within the couple relationship. Investigators examined achievements of responsivity based on the degree of the father's involvement. Although using a qualitative method, this approach and outcome is similar to Barnett and Baurch (1988) and Radin's (1982) identification of the amount, time and frequency fathers participated in their child's life.

Matta and Knudson-Martin (2006), found that father involvement could be further categorized into low, moderate, and highly responsive fathers. The identification of highly responsive fathers mirrors the fathers in my study and closely emulates the supporting categories of *being there and family/marital relationships.* Highly responsive fathers are defined as fathers who were highly attuned to their wives and children's needs. This level of responsivity developed a greater degree of marital satisfaction, involvement with their children and responsibility in the household.

Other literature supported the theme of *taking care of business.* In Bristol, Gallagher, and Schopler (1988) study of 31 developmentally disabled and 25 non-disabled boys, the father's acceptance or rejection of the child with a chronic health condition strongly affected the entire family. The study found a correlation between the amount of shared task involvement and expressive support, on one hand, and reduced depression, happier marriages, and better parenting, on the other hand. Although mothers of disabled children carried a disproportionately heavier burden than mothers with nondisabled children, father involvement in both sets was vital to the well-being of the family unit. Fathers who were especially involved with their disabled children were a critical source of support within the family.

*Transformed Fathering*

Gutmann (1997) posed several question in relation to gender identities. His assertions about Mexican male identities were very poignant to me. What does it mean to be a man? What does it mean to be a father? In fact, male identities are defined by Gutmann as "what men say and do *to be* men rather than what men say and do" (p. 17). *To be* in this context, is an infinitive that implies a continuous action, a state of continuous action. This thesis is analogous to Stryker's theoretical argument of *identity salience* when he asks the question "Why does a person select one behavioral option over another in a given situation when both options are available to the person?"

According to Stryker (1980), such talk indicates the salience of the fatherhood role to the man, demonstrates the positive dyadic relationship between the father and

child, and shows how father-child interaction is affecting the man as a father. The father's commitment to participate in his child's physical therapy and night care takes priority over his choice to attend a basketball game with his coworkers. The consequence of this choice may be a drastically altered social life with the "guys," but the interaction also fosters a stronger relationship between the father, child, and mother. Therefore, the man must struggle between the *culture* of fatherhood—that is, the norms, values, and beliefs surrounding men as parents—and the *conduct* of fatherhood—that is, what fathers do, or their reactions, responses, and interpretations of internal and external symbols (LaRossa, 1997). With this in mind, the theory of *transformed fathering* closely mirrors the Stryker's (1980) framework. However, Stryker's framework does not address or examine culture or ethnic influences that may shape the way one thinks and acts.

*Summary*

Recent research on parents of children with chronic health conditions is promising. However, there remains a gap from a father-centered perspective, the father's response and reaction to his child's chronic health condition. The fact that mothers play an important role in the lives of their families and children who have a chronic health condition is an important fact not to be overlooked. However, to ignore a father's role in the family, the dyadic relationship he has established with his child and not include him in his child's plan of care perpetuates negative stereotypes of men and fathers. Moreover, it conveys to the father that he is insignificant in this relationship, therefore promoting feelings of diminished self-worth, self doubt, and insecurities about his level

involvement. Men as fathers are changed by their experiences and capacity to relate to others. How men engage in parenting is significant not only to the child but also to the men and their familial relationships.

## Limitations

As a naturalistic inquirer, part of my responsibility as a researcher is to allow the inherent complexity of human behavior to unfold while the participant explains his or her lived experience. This experience is collected and analyzed with the sole intent of letting the data reveal thick descriptions of human realities (Lincoln & Guba, 1985; Polit & Hungler, 1995). The findings and analysis was not superficially collected and the data has provided a rich, in-depth inquiry on a little known concept. As has been presented there is very little research from a father-centered perspective that has examined fathering of children with chronic health conditions, moreover, Mexican-American fathers.

Three limitations were identified in relation to this study. First, those identified as the "gatekeepers" of the community approached this project with skepticism. The "gatekeepers" identified were the social workers and caseworkers who worked closely with families who had children with a chronic health condition. The multiple techniques utilized to recruit participants and the implied and explicit attitude demonstrated toward me about the subject matter of the project; discouraged me and hindered access to more fathers. In most cases, the mothers of the children encouraged fathers to participate and contact me. If it had not been for the three site directors in the San Antonio and Austin area, who identified fathers who participated in their programs, I would not have had

access to these fathers. While this limitation does not effect the utilization of the data for further analysis, it does present an area of bias.

Secondly, there were fathers identified who declined to participate in the study. They believed that they could not find adequate time to spend with me for an interview. This may reflect these fathers more traditional view of their gender-typed fathering role. Fathers that are more traditional may be less inclined to see the value of their participation in research. The traditional role usually typifies Mexican-American fathers as the primary breadwinner and disciplinarian while the wife takes on the day-to-care of the child. Consequently, fathers may not see the importance of their role in family research and place nominal value on participation (Galanti, 2003).

Thirdly, a majority of these fathers were middle-class fathers who spoke English. Consequently, they had more access to health care, were involved in programs that catered to their child's needs and had resources to research their child's chronic health condition. According to

## Recommendations

*Nursing Practice*

Laying the foundation of becoming an effective and efficient nurse is addressed while someone is in his or her nursing program. Child Health has as its core philosophy the promotion of family-centered nursing care. This means that the family is the constant in the child's life "while the service systems and support personnel within those systems fluctuate" (Barrera & Hockenberry, 2007, p.13). The term family constitutes different

meanings based on a person's frame of reference, value judgment, or discipline. The concern here is not to define family, but in the context of these fathers and families experiencing having a child with a chronic health condition, this project foci is on the fathers of children with chronic health conditions.

It is important for nurses to utilize a developmental approach when assessing families who have a child with a chronic health condition. By this I mean, that nurses should include a family assessment whereby their assessments include: adequate resources, number of family member in the home, primary caregiver, who works outside the home, and number of siblings.

We teach nursing students that as part of their journey to becoming a nurse, they should recognize their own values and beliefs about a culture or ethnic group in order to address preconceived notions that might hinder the care they provide to a client and their family. One important aspect is not to assume that because a father is not attending all appointments, is not a permanent resident in the home, and is not at the bedside when the child is hospitalized, that his child's chronic health condition has not affected him. Often nurses negate the role fathers have in their child's life or how their child's health affects them as men: not so much in our speech, but in our actions. Parenting classes, discharge instructions are often directed toward the mother of the child, with little regard to include the father or encourage the father to be present. Those exposed to this study and the theory of *transformed fathering*, could develop a deeper appreciation of these fathers and

tear down barriers that blind nurses to consider a father's participation in their child's care.

Thirdly, nurses should participate, advocate, and facilitate communication between physicians, therapist, case managers and social workers who play a vital role during the discharge process. Collaborative management between parents and multidisciplinary healthcare professionals is an essential component in understanding and managing their child's healthcare needs, which includes deciding appropriate interventions for their child who has a chronic health condition (Harrison, 1993, Harrison 2001, Penticuff & Arheart, 2005).

There are ways that nurses can influence an entire nursing unit's approach toward fathers of children with chronic health conditions. These ways include involving the father in the care of their child when they are at the bedside, designing parenting classes and discharge teaching around times when fathers are most available (e.g. on the weekend or after work), and begin a support group in which the foci is on fathers of children with chronic health conditions. More importantly, change begins with the individual nurses' perspective of fathers of children and cascades to those who he or she may have contact.

*Research*

While there has been an increase of research in fatherhood, there has been little research-examining fathers of children with a chronic health condition. Nurses can make an impact in this area of research because of their relationship with families when their

child is admitted to the hospital or seen at the clinic. Recommendations for future research include:

1. A study of *transformed fathering* should be undertaken to expand the theory to more diverse population of fathers. Examining fathers from diverse backgrounds would allow varying viewpoints and acknowledge that fathers' concerns about their child are important. These diverse populations should include fathers from different socio-economic, ethnic and culture backgrounds. Likewise, a comparison study that engages fathers across groups would also enrich the theory. As McCubbin, Thompson, Thompson, McCubbin and Kaston, (1993) suggest, culture and ethnicity play a large role in how the family responds to the condition.
2. Another direction for future research is to examine recruitment procedures for minority fathers of children with a chronic health condition. Recruiting minority participants has been of concern among researchers (Williams & Corbie-Smith, 2006). However, recruiting minority fathers appears to be problematic. Why a father does or does not participate in a research endeavor that specifically targets a population similar to his own, would be worth examining. As with this study, fathers may feel that their views about how their child's health condition has affected them is inconsequential. Have researchers given fathers an opportunity to participate or encouraged them to participate? Or has a researchers own bias precluded a supportive inclusion of fathers as participants? Perhaps a survey or questionnaire sent to fathers or distributed when fathers come to clinical visits

might offer insight into what factors are associated with a low participation rate. This would give an insight to specific recruitment strategies. According to Cox and Costigan (2001), there is no empirical evidence that suggest why fathers are more difficult to recruit. The answer may lie in the fact that researchers have a predetermined notion that mothers are more available and have not investigated their own bias of what motivates or does not motivate father participation in research studies.

3. I believe there is still hesitancy among minorities to participate in research studies. This in part is due to the perceived and real abuse of research methods in the past that continues to influence present day research efforts. However, I also believe that continued use of minority researchers to participate in minority recruitment is an answer. Moreover, the value researchers place on the utilization of participants and examining areas that have traditionally been overlooked might influence the inclusion of minority participants. As Cox & Costigan (2001) suggest, there needs to be more attention made to recruitment strategies and the representation of fathers who are ethnically diverse. Their prospective on family research is rich, but how to involve them in the process is one that should consider a fathers point of view.
4. Future research should also include a comparative analysis of Mexican-American fathering roles among fathers who have a child with and without a chronic health condition. This type of study would lay a foundation of establishing fathering

among a diverse group of men, approaching these studies from a father-centric approach would strengthen the research literature on fatherhood, and further test the theory of *transformed fathering* broadly.

*Public Policy*

There are many national and state level organizations that recognize fatherhood and its effect on child development (e.g. *National Fatherhood Initiative, Center for Family Policy and Practice, National Compadres Network, and the National Latino Fatherhood and Family Institute*). However, one thing that struck me with each of the participants for the study was a lack of knowledge about any local support groups or services aimed toward meeting their needs. Some of these fathers verbalized concerns that they were in a vacuum, they were surprised that "others" had a son or daughter with the same chronic health condition. Particularly that those other men had some of the same concerns about their child.

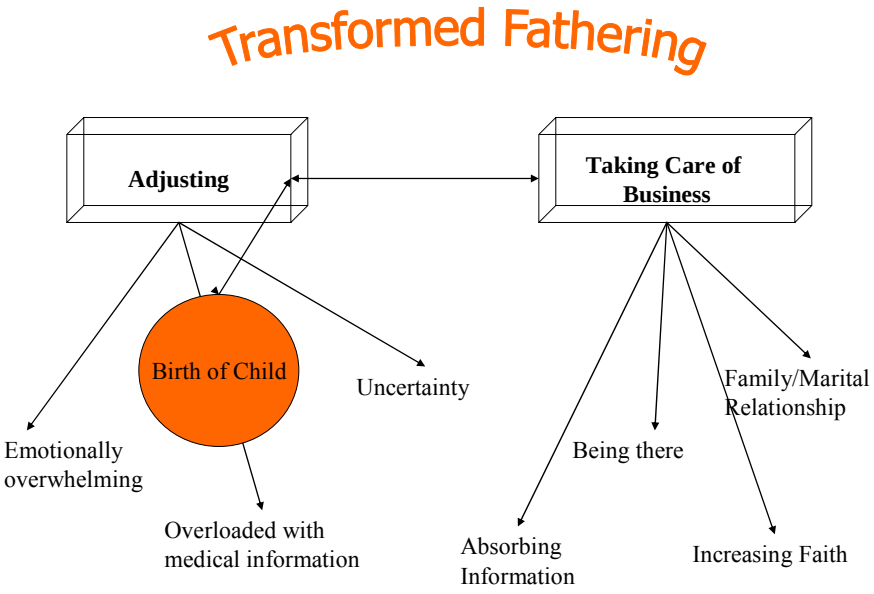
Participation in public policy at the national and state levels can influence the needs at the local level. Nurses have influence by utilizing the relationship of politic and policy that will affect professional organizations and a community's approach to fathers of children with chronic health conditions (Mason & Leavitt, 1993). Developing health promotion programs in communities serving Mexican-American families, especially Mexican-American fathers, will invite them to lend their voice and mentor others who will have to navigate the systems associated with their child's chronic health condition. Including Mexican-American community leaders and fathers of children with chronic

health conditions will assist in making programs effective and foster community involvement.

## Conclusion

In this chapter, I have summarized and reviewed the research project and the ensuing theory. I have re-examined literature as it relates to the three themes and supporting categories of *transformed fathering*. I have presented conclusions to the study, have described limitations, and have offered implications for nursing, research and public policy. I believe that the overall implication for this project is to raise awareness and motivation of all those associated with fathers and families of children with chronic health conditions. The motivation is to set aside assumptions and seriously consider the impact the child's chronic health condition has on men, on Mexican-American fathers.

APPENDIX A


Transformed Fathering
Adjusting
Taking Care of Business
Birth of Child
Uncertainty
Emotionally overwhelming
Overloaded with medical information
Being there
Family/Marital Relationship
Absorbing Information
Increasing Faith

APPENDIX B

Calling all Fathers

Do you know a Mexican-American father who has a young child (5 years or younger) with a chronic health problem?

I am seeking these men for a study of:

**MEXICAN-AMERICAN MEN'S FATHERING OF CHILDREN WITH CHRONIC HEALTH CONDITIONS**

**Goal of the Study**: To understand how Mexican-American men do the work of fathering their young children. This includes the work they do as fathers, what they think about fathering, and what they know about being a father of a child with a chronic health condition.

**Why is this Important**? There is very little information available about fathers who are Mexican-American, and even less is known about fathering of young children who have chronic health conditions. This information is needed to help improve nursing practice and health promotion programs in communities serving Mexican-American families.

IF you are interested in knowing more about this study, or know of someone who would be interested in participating, please contact Ramona Parker by phone at 210.829.3993 or email rparker009@satx.rr.com

Thank you,
Ramona Ann Parker, MSN, RN, Doctoral Candidate (UT Austin)
University of the Incarnate Word Faculty, School of Nursing and Health Professions

## APPENDIX C

Title: **Mexican-American Mens' Fathering of Children With Chronic Health Conditions**

Conducted By: **Ramona A. Parker, MSN, RN,** doctoral student at The University of Texas at Austin School of Nursing, 210/829.3993.

**Sharon D. Horner, PhD, RN,** supervising faculty, The University of Texas at Austin School of Nursing, 512/471-7951.

You are being asked to participate in a research study. This form provides you with information about the study. The person in charge of this research will also describe this study to you and answer all of your questions. Please read the information below and ask questions about anything you don't understand before deciding whether or not to take part. Your participation is entirely voluntary and you can refuse to participate without penalty or loss of benefits to which you are otherwise entitled. You can stop your participation at any time by simply telling the researcher.

**The purpose of this study** is to gather information from Mexican-American fathers who have a child with a chronic health condition to learn about fatherhood.

**If you agree to be in this study, we will ask you to do the following things:**

- Complete a general information form (age, name, occupation).
- Participate in an interview about fatherhood and being a father to your child with a chronic health condition. The interview may last 60-90 minutes and will be audiotape recorded.
- Some fathers will also be asked to take part in a second shorter interview (about 30-45 minutes) to review summaries of the themes or main points learned in the first interviews so that fathers can make some points clearer or add new ideas to the discussion.

**Total estimated time to participate** in this study is 2.0 hours.

**Risks and Benefits** of being in the study

- The risk associated with this study is no greater than everyday life.
- There is a slight risk of psychological or emotional stress as the fathers discuss what having a child with a chronic health condition means to them. The father can stop the interview or take a break at any time to deal with this stress. If the father has a need to have counseling about his

child's chronic health condition and the health condition's affect on him, a counseling agency's name and phone number will be made available to him.

- There is a risk of loss of confidentiality as some fathers were nominated for participation by family members or friends. Protection of confidentiality is described below.

- There are no benefits for participation in this study.

- There is no financial compensation for participation in this study.

- There is a risk that in some interviews information about child abuse in the family will be discussed. If this happens, I am required by law to report the abuse or suspected abuse to Child and Family Protective Services, 1-800-252-5400.

**Confidentiality:** The interviews will be audiotape recorded. To protect confidentiality only false names will be used instead of the fathers' names on the tape label and in the transcriptions of the interviews. The tapes will be kept in a locked file in Miss Parker's office. The audiotapes will only be listened to for the purpose of this study and heard by Miss Parker and the people on the research team. These other research team members include the person who transcribes the audiotapes into a printed document, and a bilingual research assistant who is helping Ms. Parker interview fathers who speak Spanish. The tapes will be erased when the study is over.

The **records** of this study will be stored securely and kept private. Authorized persons from The University of Texas at Austin, and members of the Institutional Review Board have the legal right to review your research records and will protect the **confidentiality** of those records to the extent permitted by law. All publications will exclude any information that will make it possible to identify you as a subject.

**Contacts and Questions:**

If you have any questions about the study please ask now. If you have questions later or want additional information, call the researchers conducting the study. Their names, phone numbers, and e-mail addresses are at the top of this page.

If you have questions about your rights as a research participant, please contact Clarke A. Burnham, Ph.D., Chair, The University of Texas at Austin Institutional Review Board for the Protection of Human Subjects, (512) 232-4383.

***You will be given a copy of this information to keep for your records.***

**Statement of Consent:**

I have read the above information and have sufficient information to make a decision about participating in this study. I consent to participate in the study.

Signature:_____ Date: _____

_____ Date: _____
Signature of Person Obtaining Consent

Signature of Investigator:_____ Date: _____

## APPENDIX D

## DEMOGRAPHIC DATA SHEET

Education

_____

Occupation_____

Work status

Full-time _____ Part-time_____Unemployed_____

Marital Statues

Single_____Married_____Divorce_____Separated_____

Non-married, but living together_____

Number of children living in the

home_____

Born in the United States Yes_____ No_____

Years living in the United States_____

## APPENDIX E

## INTERVIEW GUIDE

1. Tell me about (child's name…..)
2. Tell me about your child's chronic health condition as you understand it?
3. What is your role or activities as a father in your family?
4. When you compare yourself to other men who are father (who have typically developed children),in what way are you different and in what way are you the same as they are as fathers?
5. How has being a father changed you as a person?
6. Has (child's name) affected your role as a father?
    a. How has your child's (chronic health condition) affected who you are or the quality of your life? That is, has it caused you to develop differently than you would have developed had you never been a father?
    b. Is your relationship with (child's name) the same or different from your other children?
7. Has your experience as a father affected your view of your own parents? Give an example or explain.
8. Do you have any closing thoughts on fatherhood? Any areas that we haven't discussed that you feel are important to consider?

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# Vita

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